

EDUCATING OLIVER

A CASE FOR SPECIAL TREATMENT 1982-2007

PHILLIP MEDHURST

WITH THE DOCUMENTS OF OLIVER'S FATHER

EDITED WITH PERMISSION BY

HARRY KOSSUTH

IN TWO PARTS

PART 2: WORCESTERSHIRE. 1986-2007

including an appendix with the full text of

“FIGHTING BACK”

The HEADSTART FOR

OLIVER (H.O.P.E.)

programme

1984

for PART 1: LEICESTERSHIRE. 1982-1985 see

<http://www.archive.org/details/EducatingOliver.Part1Leicestershire>

<http://www.scribd.com/doc/17605113/Educating-Oliver-1>

<http://books.google.com> GGKEY 7H1CYHD6UFX

for recent news about Oliver see

http://www.redditchadvertiser.co.uk/search/1697311.Burglary_brings_birthday_misery

<http://archive.worcesternews.co.uk/2007/9/18/484539.html>

http://www.redditchadvertiser.co.uk/news/1712448.residents_moved_by_olivers_plight

<http://archive.worcesternews.co.uk/2007/9/25/485637.html>

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PART 2: WORCESTERSHIRE

TEN YEARS ON: SOME REFLECTIONS

In some ways the pain increases as time goes on. Those dreams which gave hope are gradually seen to be delusions rather than visions.

Our hope that Oliver would recover some functional use of his limbs has not been fulfilled. If anything, we have seen a deterioration as joints have calcified, unused muscles have wasted, and contractures have become more severe. Major spinal surgery was necessary (in 1990) to stabilise his posture. In 1987 a bout of nearly-fatal pneumonia was a shock which raised a host of forgotten demons.

No speech has returned. Some days before his accident Oliver had won a choir-scholarship at Leicester Cathedral. It is still impossible to hear a boy singing without acute emotional pain. Knowing through a simple "Yes/No" code that Oliver was intellectually intact, we placed great hopes in technology, and I became something of an expert in this rapidly developing field. But it was all in vain. While computers have provided Oliver with some worthwhile educational activities, they have not proven to be the panacea we expected. Oliver's particular pattern of visual difficulties and cerebral-processing problems means that use of the equipment is slow and frustrating.

Perhaps the greatest blow was having to "admit defeat" and send our son away to boarding school. By 1985 we were emotionally drained and exhausted and our teenage daughter was beginning to react. Our attempts to obtain adequate resources in the community became a running battle. My career, our means of livelihood and financial independence, was beginning to suffer. Our dwindling social relationships were dominated by our constant demands on a small, forbearant circle of friends whose "normal" family pre-occupations became increasingly remote from our own. Eventually, the time came for us to swallow our pride and our deep sense that we were betraying Oliver, and ask for a residential placement. Since 1985 Oliver has spent only three months of the year at home. This has given us time to adjust as far as possible and to prepare for the very demanding arrangements that will come into operation when Oliver comes home permanently in 1993.

**Letter. 15 November 1989. To: The Headmaster, Penhurst School,
Chipping Norton, Oxon.**

Dear Mr. S.,

OLIVER WILLIAM MEDHURST. [D.o.B. 10-09-73]
1981 Education Act
Further Parental Representations

Thankyou for chairing Oliver's Review meeting at Penhurst on the 10th.
Handling a meeting of such size required great skill and we were very pleased
that you were able to ensure that the occasion was both productive and
informative.

Having reflected on some of the contributions to the discussion we feel that we
must express concern about one or two matters relating to the two items on the
agenda. Given the increasing urgency of the situation we must, perforce, be
very direct.

16+ PLACEMENT

We were surprised at how little specific information there appeared to be about
appropriate institutions available to the meeting; such information is now a
matter of urgency. We would suggest approaches to the following
schools/colleges:-

Beaumont College of Further Education,
Slyne Road,
Lancaster LA2 6AP
[0524] 64278

Dene College,
Shipbourne Road,
Tonbridge,
Kent TN11 9NT
[0732] 355101

Nash House,
Coney Hill School,
Hayes,
Bromley,
Kent BR2 7AG
01-462 2017

Meanwile, we note that representatives from Portland College will be visiting
Penhurst for the purpose of assessing Oliver today. Ms. K. has promised us a
copy of their report and we will study this with great interest.

MICRO-ELECTRONIC AIDS

We very much hope that Mr. M. will obtain leave from Hereford and Worcester Education Authority to follow through his preliminary assessment of the 5th January 1989. It seemed apparent at the meeting that your Mr. W. had [potentially] a great deal to say about Oliver's needs. Once again, it was a pity that more specific information was not available to the meeting. Oliver's progress [or lack of it] so far needs to be considered. You may recall that I asked for a Report specifically from Mr. W. in a letter dated 8 Oct. 1986. In your reply of 15 Oct. you assured me that he would provide one. In the event, a report did not appear. My plea to him was re-iterated during our discussions on the 5th of January this year; once again to no effect. I am therefore once again obliged to ask

THAT Mr. W. [N.C.H. Micro-electronics Resources Adviser] be asked to provide a detailed report on Oliver's work with such equipment since 1985, but with particular reference to the current programme. This Report should indicate
Hardware currently in use;
Software currently in use;
The skills which are being developed, and how;
Oliver's current rate of progress and how this is being assessed.

We feel that it is reasonable to ask for such a report to be available before Easter 1990; it is, we feel, an essential tool in promoting Oliver's progress beyond the age of 16. In the few years that remain of Oliver's formal education we cannot afford to waste time "re-inventing the wheel".

We look forward to a fruitful outcome to the statutory re-assessment process; meanwhile, many thanks for the part you have played in what progress has been made so far.

Copies to:-

Mr. J. W. T., Education Dept., Castle St., Worcester WR1 3AG
Mr. A. S., Education Dept., Castle St., Worcester WR1 3AG
Mrs. P. P., Education Dept., Castle St., Worcester WR1 3AG
Miss D. D., Education Dept., Castle St., Worcester WR1 3AG
Mr. J. T., Education Dept., Castle St., Worcester WR1 3AG
Ms. P. A. C., Education Office, County Buildings, Bewdley Rd.,
Kidderminster DY11 6RQ
Mr. D. M., County Micros Centre, Perdiswell, Worcester
Cllr. J. G., 96 Stourport Rd., Kidderminster
Mr. D. S., Penhurst School, Chipping Norton, Oxon.
Mr. M. W., Penhurst School, Chipping Norton, Oxon.
Ms. J. K., Portland College, Harlow Wood, Mansfield, Notts. NG18 4TJ

Circular. 10 November 1989

Parental Representations. Education Act 1981.

1. PREAMBLE

In this statutory re-assessment of our son's special educational needs we wish to focus on one crucial aspect: namely, micro-electronic resources which may further Oliver's education towards any degree of independence which he may enjoy in the future. Such independence falls into two categories:

- [a] COMMUNICATION. [Oliver cannot talk]
- [b] CONTROL. [Oliver has little functional movement]

2. THE CURRENT SITUATION

The statutory agencies have provided two pieces of equipment:

- [a] A "Light-Talker", on loan from Leics. Speech Therapy Dept. Input: single-switch operated by the head. Process: visual scanning by L.E.D. of "Minspeak" symbols. Output: synthesised speech; one-line liquid-crystal display.
- [b] Two P.O.S.S.U.M. switches for head-usage mounted on a microphone-stand, provided by Leics. Health Authority.

3. IDENTIFIED NEEDS

- [a] Oliver has no equipment for computer-assisted learning [C.A.L.] provided by a statutory agency.
- [b] Oliver has no C.A.L. equipment for homework.
- [c] Oliver has no environmental control system.
- [d] In any 16+ placement Oliver will be expected to bring his own equipment to the receiving institution.

4. PROPOSAL

THAT Hereford and Worcester Education Authority provide equipment on which to base Oliver's education up to the age of 19 in the areas of C.A.L., communication, and control. Correlations may be made between these areas and the subjects laid down in the National Curriculum.

This proposal relates to the fact that the "Light-Talker" may be interfaced with a computer-system, enabling input by Oliver to such a system. The technical parameters of the necessary system are as follows:-

- [a] processor: I.B.M.-compatible 256K - 640K Portable or "luggable"
- [b] data storage: Dual disc-drive MS-DOS

- [c] display: Conventional V.D.U. or gas plasma
- [d] output: Serial port [RS 232C] Other ports if possible
- [e] interface: From LIBERATOR, suppliers of the "Light-Talker"

5. IMPLEMENTATION

Our experience over the last seven years indicates that resources are only likely to be made available and/or used if professionals involved with Oliver feel that they have direct control over the provision. The problem at the moment is that in the current situation the "buck" is likely to be passed between either the different statutory agencies, or the statutory agencies and the receiving institutions, or different possible receiving institutions, or professionals within a statutory agency, or professionals within receiving institutions, or agencies/institutions and charities, or different charities.

Meanwhile, Oliver's needs remain unmet.

As far as we are concerned, responsibilities should be allocated as follows:-

[a] Provision and servicing arrangements: Hereford and Worcester Education Authority [Mrs.Cooper]

[b] Technical advice and recommendations: Hereford and Worcester Education Authority [Mr. Mitchell]

[c] Development and usage: receiving institution [member of teaching staff responsible for micro-electronic resources]

Unless we are informed otherwise, we will assume that the above are to be regarded as the accountable agents in any correspondence with the appropriate authorities or with our representatives.

Copies to:-

Mr. J. W. T., Education Dept., Castle St., Worcester WR1 3AG

Mr. A. S., Education Dept., Castle St., Worcester WR1 3AG

Mrs. P. P., Education Dept., Castle St., Worcester WR1 3AG

Miss D. D., Education Dept., Castle St., Worcester WR1 3AG

Mr. J. T., Education Dept., Castle St., Worcester WR1 3AG

Ms. P. A. C., Education Office, County Buildings, Bewdley Rd., Kidderminster DY11 6RQ

Mr. D. M., County Micros Centre, Perdiswell, Worcester

Mr. D. S., Penhurst School, Chipping Norton, Oxon.

Cllr. J. G., 96 Stourport Rd., Kidderminster

Letter. 17 November 1989. To: Ms. P. A. C., Hereford and Worcester County Psychological Service

Dear Ms. C.,

Thankyou for your letter of 9th November 1989. I remember well the content of our meeting last summer. In view of your proposed course of action at that time, and in view of this re-iterated statement of your adopted role, we would be very grateful if you would take particular note of our remarks under the heading "16+ PLACEMENT" in our "Further Parental Representations" of the 15th of November. Although it is now too late for the Leaver's Review, we nevertheless await any advice which you have to offer with eager anticipation.

Copies to:-

Mr. J. W. T., Education Dept., Castle St., Worcester WR1 3AG
Mr. A. S., Education Dept., Castle St., Worcester WR1 3AG
Miss D. D., Education Dept., Castle St., Worcester WR1 3AG
Mr. J. T., Education Dept., Castle St., Worcester WR1 3AG
Cllr. J. G., 96 Stourport Rd., Kidderminster

Letter. 11 September 1991. To: The Rt. Hon. A. M. V. C., M.P., Margaret Thatcher House, 35 Mill Street, Kidderminster, Worcs. DY11 6XB

Dear Mr. Coombs,

Thankyou for your letter of The 9th September 1992. Oliver's preferred solution to the complications that seem to have arisen is a fresh two-year placement. He is therefore particularly concerned about the response of the Authority to his acceptance of the offer of a place at Hereward College, Coventry – particularly in view of the fact that their term began on 2 September. After careful consideration of all the information currently at his disposal, Oliver has expressed to us a desire not to return to Nash House. He looks forward to hearing anything positive very soon. We hope that he will not be disappointed!

Copies to: Cllr. J.G. (Hereford & Worcester County Councillor)
Cllr. R. M. (Hereford & Worcester County Councillor)
Cllr. D. M. (Chmn., Education Committee)
Mr. R. L. (Senior Careers Officer)
Ms. P. B. (Specialist Careers Officer)
Mr. A. S. (Asst. Dir. of Education, Pupil Services)
Mr. J. T. (Statementing Officer)
Mr. ? R. (Placements Officer?)
Mrs. P. C. (Educational Psychologist)
Mrs. D. H. (Principal, Nash House)
Mr. R. W. (Principal, Hereward College)
Mr. O. P. (Investigator, Local Government Ombudsman)
Dr. P. C. (Consultant Paediatrician, Lea Castle Hptl.)
Rt. Hon. T. H., M.P. (Under-Secretary of State for Ed.)

Leaflet. August 1992

We rejoice that our son lives. He is a joy to be with. His radiant personality and wonderful sense of humour transfigure the pain and tragedy of his situation and the bleakness of his future. We, his parents, are committed to caring for him as long as our strength endures. Even if physically hard, it is not a sad and demoralising task: we love our son, and he gives us much in return. But there are shadows which fall across our home. We have come to know our limitations. The time has come once again for us to swallow our pride and seek the help of the community.

Having shared our story, are you willing or able to help us? If the answer is "Yes", then please read on

THE OLIVER MEDHURST APPEAL. 1992-3

PLEASE consider the following:-

1. OLIVER is now 18. He returns home "for good" in 1993.
2. Mobility is the key to OLIVER's quality of life. Getting "out and about" in his wheelchair is essential for this teenager, who can do so little to entertain himself.
3. The Medhursts are obliged to be a one-income family. Their only means of transport in an unadapted Metro. OLIVER has to be lifted bodily in and out. Both parents have had to seek medical help with back pain.

17 AUGUST 1992 IS THE TENTH ANNIVERSARY OF OLIVER'S ACCIDENT. HE COMES HOME ONE YEAR LATER. CAN YOU HELP?

Our need is for a special "roll-on/roll-off" vehicle that will enable any carer to load OLIVER onto a vehicle without physical risk to themselves. Such vehicles do not come cheap. We estimate that we need at least £20,000 to purchase one. We do not have the financial means, but we are convinced that this is not a luxury if OLIVER is not to become a prisoner in his own home.

PLEASE FILL-IN AND RETURN THE FORM OVERLEAF

Letter. 26 April 1992. To: The Head of Care, Hereward College, Coventry

Dear Ms. Kendrick,

Oliver has asked us to write to you to point out that he has just purchased a "Discman" and is quite keen on taking it around with earphones during the day to play at appropriate times. There is a set of speakers in lieu of the earphones to use in his room at other times. Could you please bring the attached notice to the attention of colleagues or place it on display in his room? With thanks.

please . . .

1. place a disc in the player
2. attach the player to Oliver by means of the strap
3. connect the earphones
4. press the play button (far right on console)
when appropriate . . .
5. plug speakers into earphone socket
6. plug speakers into mains
7. plug disc-player into mains to save battery

Letter. 26 April 1992. Dr. R. West, Access Centre, Hereward College, Coventry

Dear Bob,

When we last saw you, we mentioned the need to give Oliver's sponsors some occasional feedback.

The lady who provided the funds for all of Oliver's Toshiba equipment is:-

Mrs. J.H. B. (*address*)

She learned of Oliver's situation by accident just over a year ago and has been extremely generous since then. Although we correspond, no-one in the family has met her in person. I guess she must be in her sixties and a widow.

A letter from Oliver of a positive kind produced on appropriate equipment would be very apposite at this time.

Letter. 1st August 1994. To: whom it may concern.

OLIVER MEDHURST - SPIRITUAL NEEDS

Oliver took up permanent residence in "Saltways" Cheshire Home, Redditch, on 1st August 1994. To those who have not a great deal of experience with the cerebral palsy, Oliver's handicaps can be daunting: he only has limited functional movement in his head, and no speech. The "shock-value" of his handicap is compounded by the fact that his condition arises from a road-traffic accident when he was eight years old. (Oliver's d.o.b. is 10.09.73; the date of the accident - 17.08.82 - is a particularly sensitive anniversary for the family.)

In view of the initial impact of his condition, it is necessary to remind interested parties of the following:-

(a) Oliver is of at least normal intelligence, although his condition means that he is sometimes unable to inhibit socially inappropriate reactions (eg. laughter during sermons or at solemn moments in liturgy).

(b) Oliver is a sincere Christian and particularly enjoys religious music and worship. He has received the (Catholic) sacrament of anointing wherever possible and would wish to receive this in the company of those close to him whenever auricular Confession would be appropriate for other Catholics.

SPIRITUAL HISTORY

Oliver was baptised and confirmed as an Anglican (his father was an Anglican priest). He was received into the Catholic Church with his parents in 1988 and confirmed a year later. (Oliver's father is now an R.E. teacher in a Catholic secondary school. His adult sister remains a non-practising Anglican.)

Oliver went on a pilgrimage to Lourdes with his parents in 1988, shortly before being "received". In 1989 he went on a pilgrimage to Rome with ACROSS and was individually blessed by the Pope.

Oliver's Sunday observance has been to a certain extent disrupted by residential education, although it should be said that Oliver enjoys the worship of all denominations and is thoroughly ecumenical in outlook. During 1988-90 he attended Chipping Norton (C of E) parish church while attending Harvington (R.C.) church at weekends. During 1990-94, while attending FE College, attempts to establish attendance at Tile Hill Catholic church in Coventry came to nothing owing to problems of communication and logistics. During occasional week-ends at home there was an attempt to establish a relationship with St Ambrose Kidderminster, but again logistics have frequently overcome Oliver's intention.

Oliver was prepared for Confirmation in Kidderminster by a Trinitarian sister; the Order left the area soon afterwards. Since 1989 he has received little and latterly no pastoral ministry from the Church beyond brief greetings on the occasional Sunday morning.

At the time of writing (13.08.94), it is the joint intention of Oliver and his parents to attend the 11 o'clock Mass at Our Lady of Mount Carmel in Redditch. This will involve some degree of travel on the part of Oliver's parents. Since his mother is now unable to lift at all and his father is unable to lift him single-handedly this intention is dependent on the availability either of paid care or of the Home ambulance with hydraulic tail-lift on Sunday mornings.

Letter. 28th August 1994. To: whom it may concern

OLIVER MEDHURST - SPIRITUAL NEEDS

Further to our memorandum of 13.08.94 concerning our son – now a resident of "Saltways" Cheshire Home in Redditch – we have pleasure in enclosing a cutting from "The Universe" of 28.08.94 showing a photograph of Oliver at last Sunday's diocesan pilgrimage to Harvington. Thankyou for your tolerance towards our attempts to act as our son's advocates during this initial phase of his re-location.

Letter. 22nd August 1996. To: Mr J. B. The Disability Team, Wendron Centre, Chapel Street, Bromsgrove, WORCS. B60 2BQ

Dear Jack,

OLIVER MEDHURST - FINANCIAL MATTERS

We enclose a copy of a letter which we have sent to L. H.C.

As you will know, the ILF grant came into operation on 25 July 1996. We are hoping to start paying invoices for afternoon care directly from 3rd September. It would be helpful if you could send us the following:-

- (a) An invoice for afternoon care between 25 July and 26 August; we will be able to pay this immediately.
- (b) An invoice for "extra" (ie. evening and night) care during the period 7-22 August; we will pay this just as soon as we have accumulated funds from savings elsewhere (eg. suspension of afternoon care 27 August to 2 September).
- (c) An invoice for Oliver's own personal financial contribution to care to date.

We enclose a invoice which we have received from The Winged Fellowship. Please note that they are still holding a £50 deposit paid by us.

Letter. 25th August 1996. To: Mrs L. H.-C. Independent Care Service, "Sandalwood", 25 Comberton Road, Kidderminster, Worcs. DY10 3DL

Dear Mrs H.-C.

OPERATIVES FOR THE OLIVER MEDHURST HOME

Please accept our grateful thanks for all your good services in providing care for Oliver during our annual holiday 7-22 August.

We are now writing to inform you that as from Tuesday 27 August the funding arrangements for daily care for Oliver from noon onwards have changed. Agencies employed for afternoon and evening arrangements are invited to negotiate terms and conditions and send invoices directly to us as Oliver's agents. (Please note that Mrs Medhurst holds Enduring Power of Attorney for Oliver's financial affairs.) Morning care will continue to be contracted by Social Services with the current arrangements unchanged.

In order to smoothe the transition to the new permanent arrangements and to review our requirements we are suspending afternoon care for the period Tuesday 27 August to Monday 2 September inclusive. The two carers involved – R. and M. - have been informed of our intention. We shall be "at home" throughout this period; please do not hesitate to phone or call to discuss future arrangements inside or outside office hours.

We hope that this hiatus can be viewed positively by you and your operatives as an opportunity to review the nature of the service you are able to offer to Oliver and the home in which he resides with us. As you know, Oliver wishes to go out and about in the afternoon whenever possible, and this is an important element in his quality of life. When the weather is inclement, there is a limit to the recreational activities which can be pursued with Oliver during the session, although we are always to co-operate with carers' own initiatives. We do not feel it appropriate to spend scarce resources on employing people to "sit" with Oliver when Mrs Medhurst can be present in the house.

As we have indicated to you before, Oliver is part of a household of three adults in which all resources and financial commitments are shared. There can therefore be no natural distinction between Oliver's "area" or "possessions" and our own. Furthermore, it is vital that Mrs Medhurst, as Principal Carer and Care Manager, does not come under undue stress. If she does, the current universally beneficial arrangement will collapse. This means that we must ask agency operatives to perform general and undifferentiated domestic duties as directed by Mrs Medhurst during inclement weather and at other times as deemed appropriate by us. If this is not acceptable to you, care may be suspended during seasons of inclement weather and a domestic help agency may be employed by us at these times, or alternative agencies or individuals may be employed who have the required flexibility.

If you or individual carers are unwilling to countenance more general domestic duties as operatives at our home then it is vital that you inform us as soon as possible during the next seven days so that we can make alternative arrangements. The current arrangement will automatically be terminated on 2 September. If, on the other hand, you and the current afternoon carers are willing to work as operatives within the terms and conditions indicated in this letter we all look forward to a resumption of their new duties on 3 September.

If we do not hear from you before that date we will assume the new arrangements are acceptable to the agency. A copy of this letter has been given to R. and M. and sent to J. B. to speed the consultation process. It would be helpful if invoices could be sent to us on a strict four-week cycle commencing 16 September 1996.

Unless we receive written information to the contrary, we are assuming that the agency will be held liable for any mishap involving Oliver or his property and any operative sent by the agency, and that the agency fee contributes towards the cost of your insurance premium.

We have all been pleased with the service we have received from you within the terms of the Social Services contract; we sincerely hope that you will feel able to offer us a comparable service under the terms outlined above. We look forward to hearing from you at any time within the next seven days.

Letter. 29th September 1997. To: J. F., Service Manager Physical Disabilities, Social Services Department, Bellway House, 7 Worcester Road, Bromsgrove, Worcs. B61 7DL

Dear Mrs F.

APPLICATION FOR DIRECT PAYMENTS FOR OLIVER MEDHURST

Thankyou for your letter of 11 September 1997.

We note that the direct payments pilot project is due to commence on 1st October 1997, and that information will be available in late September. We look forward to receiving written information when it has been published and to discussing the matter further with J. B. or P. F. as you suggest.

As part of our application for direct payments for our son we enclose a statement of our own assessment of Oliver's "formal" care needs ("informal" care being provided by ourselves).

We are now asking for assistance in approaching the I.L.F. for a re-assessment of their contribution to Oliver's care as soon as possible, prior to revising and establishing the contribution to be made by the Social Services Department. We are instigating this process on the grounds that we are currently having to subsidise "formal" care from our own pocket.

In order to prevent any delay to the possible implementation of direct payments to Oliver we would be grateful for your assistance in expediting these matters.

Letter. 13th April 1999. To: The Director of Social Services, County Hall, Spetchley Road, Worcester WR5 2NP

Dear Mr G.

We are writing to you in connection with our son Oliver, who sustained extensive brain damage as a result of a road traffic accident when he was 8 years old in 1982. Oliver is very severely physically disabled, although relatively unimpaired cognitively. Since he has no functional movement and cannot speak, he needs a high level of care on a 24-hour basis coupled with a quality of life commensurate with his intelligence and full awareness of his surroundings.

Oliver had been in residential care up till November 1995 when we took the joint decision to care for him in our home in Kidderminster. Since that time day-care has been funded by Social Services, for which we are grateful. We are sorry to say, however, that one or two problems have arisen.

Some of the day-care is contracted and managed by ourselves using monies provided directly to us by The Independent Living Fund. Other care, however, is provided by commercial agencies contracted and managed by the local Social Services offices in Bromsgrove. It is with the latter that we have experienced problems.

The commercial agencies are extremely reluctant to have dealings with Oliver's advocates and representatives – ie. ourselves – except when they are unable to provide the contracted service. At such times, it is automatically assumed that we will step into the breach. We appreciate that, human nature being as it is, a commercial organisation will be primarily interested in the opinion of the paymaster (ie Social Services). Unfortunately, the Social Workers responsible are remote from the day-to-day situation and the problems that arise, and are generally reluctant to criticise or call to account the agencies on which they depend to provide the service. Closer engagement with, and monitoring of the agencies would entail more work for the local Social Services Office – extra work which they are, not surprisingly, reluctant to embrace with open arms. Meanwhile, while we *are* willing to monitor the quality of the service, scant regard is paid to our opinions by the agencies concerned. Indeed, there has been more than a hint from agencies that criticism from us will lead to a curtailment or even total withdrawal of the service, and this implicit threat has been actualised on two previous occasions by two different agencies. The same development appears now to be under way with a third agency, and the local Social Services Office appears reluctant to grasp the nettle of restraining this potential or actual exploitation of dependence which has very much the flavour of "disciplinary" action against a recalcitrant client.

Such frustrations are tolerable provided that an efficient service is provided by the agencies. Unfortunately, in the last three years we have experienced three major crises in which the service has been severely curtailed or has collapsed altogether. In these situations it has been obvious that the local Social Services office has been completely out of its depth, and, despite its nominal role in managing the service has been unable to deal with the problem of defaults.

The first crisis occurred in January 1997 when the agency withdrew its service at short notice as part of an attempt to increase its fees. We immediately contacted our part-time Social Worker, who indicated that he was unable to help until his return to work the following week. Naturally, we "plugged the gap" ourselves, despite our employment commitments and back injuries. In the event, we were able to hire carers ourselves by "borrowing" money from ILF funds and presenting Social Services with a bill.

At this time it became obvious to us that a far more effective service could be provided for Oliver if Social Services funds were paid directly to us, thereby enabling us to hire carers ourselves (as was already happening with ILF funds). Such an arrangement would be more flexible, more efficiently managed, and have the important effect of making agencies more responsive to criticism from those fully aware of the situation on a day-to-day basis.

In view of this conviction, we were delighted to hear that in April 1997 legislation came into force which allowed local authorities to make such arrangements for "Direct Payments". Not surprisingly, therefore, we made a application for such payments in February 1997.

Since then, there has been little progress, and we are asking you to give a considered response to the following:-

1. It is now over two years since our application and the situation has not been resolved.
2. As result of a formal complaint about the delay we received an indication in July 1998 that we would be granted Direct Payments. Since then we have received no further details and there has been no observable progress.
3. No information has been provided to us regarding the operation of the scheme eg. administrative parameters for those receiving payments, the time-scale to be expected in dealing with applications, procedures for application, and officers responsible for dealing with applications.
4. Since the concerns outlined in (3) were not addressed in the response to our complaint - which seemed to consist primarily in a plea for sympathy for the professionals concerned in setting up the scheme – we exercised our right to ask that our complaint be referred to a Review Panel. This request has been ignored.
5. In the period since our application there have been two further periods of default in which we have had to make our own arrangements for hiring care by "borrowing" from ILF funds and sending an invoice to Worcestershire County Council.

It is impossible to communicate to paid professionals remote from our home situation the amount of stress which such a situation can impose on a family which already has its fair share of burdens. Indeed, this stress, which has had some medical repercussions, has led us to regard our application as for a time in abeyance. But recent experience with a defaulting agency has led us to return to our application with a renewed conviction that Direct Payments provides the only real solution to these recurring problems.

Nothing in our dealings with Worcestershire County Council – which have entailed the writing of over 30 letters on this specific issue – has dispelled the suspicion that the department responsible for handling complaints is reluctant to criticise fellow professionals in the same public service. Furthermore, our previous attempts to approach you leave us in no doubt that you will pass this letter on to a junior colleague who will have the specific brief of giving a merely self-justifying response without any attempt to move matters on in a positive way. If this happens again, we will have no choice but to refer our concerns elsewhere.

Letter. 29th May 1999. To: J. B. Social Worker, Physical Disability Team, Wendron Centre, Chapel Street, Bromsgrove, Worcs. B60 2BQ

Dear Jack

APPLICATION FOR DIRECT PAYMENTS FOR OLIVER MEDHURST (22.02.97)

Thankyou for your letters of 18 and 20 May 1999.

I hope that you are able to accept the principle that an annual budget preserves our dignity more effectively than an *ad hoc* weekly dole, and that in seeking to establish this I am not "talking a load of crap" as you asserted during our meeting on the 11 May 1999.

Unfortunately, despite our lengthy discussions with you last December, during which we thought that we were moving to respite care on a six-weekly cycle, we once again seem to find ourselves in an "*ad hoc* dole" situation. Hence our concern that respite care should be built into any proposed Direct Payments package.

You may have heard that, in the face of a direct refusal to fulfil his defined duties, an agency worker was recently sent away by Jackie. We do not feel that public money should be paid to people simply for watching T.V. in our house. Despite your re-iterated concern at the 11 May meeting that we should not be "making a profit" from Direct Payments, you will find that we have always been assiduous in pursuing value for taxpayers' money.

We look forward to hearing the results of "senior staff" deliberations soon regarding a viable level of financing for Oliver's needs which takes into account the savings to the Council which our input would bring and which would prevent us from being effectively penalised for trying to improve the quality of his care.

Editor's note: Phillip Medhurst suffered a heart-attack in October 2000. The Medhursts formally separated in 2002, and Oliver was placed in residential care.

Letter. 12 June 2003. To: C. M., Physical Disability Team, Worcestershire Social Services

Dear Ms M.

I refer to your letter of 6th June 2003.

It is a depressing illustration of the lengths to which you and your allies are willing to go to in order to undermine any attempt we may make to promote our son's welfare. As you are no doubt well aware, it was this chronic inability to listen which resulted in Oliver's current incarceration in an Old People's Home.

Be that as it may, during a visit by Mrs. Medhurst and myself on Sunday 8th June 2003 it became painfully obvious that Oliver was suffering extreme discomfort on his bottom. In our assessment, based on 20 years' close contact with our son, his weight loss is a contributory factor to this disturbing state of affairs. Our observation of his weight loss is corroborated by two independent witnesses who know Oliver well, and is undoubtedly (in our expert opinion) the result of Lickhill Manor not investing enough time and labour in his feeding regime.

As regards Oliver's quality of life, it is now painfully obvious that you intend to renege on your promise to incorporate Oliver into a Young People's Disabled Unit to be constructed on the Lickhill Manor site. Since, under Ms D.'s tutelage, with her aggressive and uncritical support of commercial organisations and her consistently hostile stance towards Oliver's parents, it would be madness for us to relinquish our close supervision of our son's care, it seems to us obvious that there are now three alternatives:-

1. Improve the style and quality of Oliver's care in his current placement;
2. Provide a more appropriate placement within the same locality;
3. Provide funding for 24-hour care in a two-bedroomed bungalow which we have acquired for this purpose in Bewdley, to be managed on site by myself, with Oliver's mother in moral and emotional support while residing nearby.

The third option precludes any *physical* input to Oliver's care by myself or Mrs Medhurst – Mrs Medhurst has a damaged back and I have cardio-vascular problems. In any case, we feel it would be foolish for us to further sacrifice our health and welfare in the face of Social Services' evident parsimony with regard to the domiciliary option and equally evident open-handedness when it comes to commercial organisations. Oliver was ejected from his own home in 2001 as a result of the under-funding of Direct Payments. Give us a budget comparable to the one being given to Lickhill Manor (including the swingeing price-rises which have gone through "on the nod"), and it seems to us that, with some minor alterations to the premises in question, we are "in business" with regard to the domiciliary option.

Provided that it gives you sufficient time to (1) do your homework on the above options (2) introduce these options to your many colleagues, and (3) enable

those colleagues to send us a written introduction to themselves and their terms of reference before the meeting, I can see no reason why the proposed meeting should not take place on 26 June 2003. I propose that this takes place at the following address:

3 Hornbeam Close
Bewdley
Worcestershire
DY12 2JP

You will no doubt write to me very soon if you prefer the earlier date, together with a list of participants and a written account of any specific proposals which you intend to bring to the meeting. You will also wish to consult with Mrs Medhurst. This will undoubtedly help to avoid the fiasco which we had to endure when we last tried to introduce proposals for our son's welfare in 2001.

Letter. 16th July 2003. To: S. D., Physical Disability Team, Worcestershire Social Services.

Dear Ms D.

I note with the utmost regret that you have ignored my invitation to a case conference for our son Oliver at the above address on 21st July. I note also that you and St Cloud Care held a case conference at Lickhill Manor on 26th June in our absence and against our express wishes. This is a very serious situation, and Mrs Medhurst and myself will be considering our response over the next few weeks.

I understand also that you have composed a letter to me dated 11th July. I still have not received this letter, although Mrs Medhurst received a copy on 12th July. It is difficult to tell whether this is the result of crass manipulation or incompetence; in case it is only the latter I will respond to some of its points.

In the as yet unreceived letter you invite me to a meeting with yourself on 31st July. Since (I have discovered) Ms M. met with Mrs Medhurst on 10th July, and since Mrs Medhurst and myself are of one mind about what is best for our son, such a meeting would be superfluous. I suggest you continue to liaise with and inform Mrs Medhurst if there are any further developments in response to our recent proposals. Not surprisingly in view of the underfunding crisis which destroyed our last Direct Payments arrangement, Mrs Medhurst and Oliver himself have mixed feelings about him joining me at the above address; unfortunately, you have deprived us yet again of the opportunity of airing our concerns in an appropriate context.

In the same unreceived letter you propose an "independent" advocate. As you are aware, when we last acceded to such a proposal we found ourselves, to our horror, dealing with an *agent provocateur* in the pay of Worcestershire County Council whose input was entirely negative. Meanwhile, our urgent pleas for the adequate funding of our son's care went unheeded and Oliver was shunted into

a (generously funded) old people's home/home for the mentally handicapped where he has remained ever since.

Our response to this unfortunate state of affairs will depend on what efforts (if any) are made to repair the damage which has been done by the department which throughout this difficult period has been under your tutelage. The style of response to our recent legitimate concerns about Oliver's weight-loss has not inspired confidence. Needless to say, as the person holding the Enduring Power of Attorney for Oliver, my approval will have to be sought and obtained for any present or future arrangement for his care.

Editor's note: The Medhursts divorced in 2004. Oliver was given the tenancy of a bungalow by a housing association (Contour Housing), and social services arranged a live-in care regime.

Letter. 28th March 2005. To: M. H., Physical Disability Team.

Dear Ms H.

I refer to my letters of 12th January and 23rd March 2005. Unfortunately, the dialogue which these letters were aimed at instigating has not taken place. Indeed, my recent attempt to establish contact with the Physical Disability Team has left a great deal to be desired. While I am happy to put money towards the *fait accompli* of Oliver's forthcoming holiday, I am not convinced that extra resources which could be made available by me would be used solely for his benefit – and not be used to relieve Social Services and those working directly with Oliver of their financial and other responsibilities.

In this respect, the experiment has revived painful memories of the Direct Payments fiasco, when the extra resources in terms of the time and energy of Oliver's parents were misused in the same way and chronic under-funding of the scheme and Social Services' refusal to heed warnings led to the collapse of the partnership, a deterioration in Oliver's quality of life, and ultimately a false economy.

As long as Social Services show a habitual tight-fistedness towards private benefactors (such as Oliver's family), a loose open-handedness towards commercial organisations (such as care agencies and transport companies), and a certain dilatoriness in the management of Oliver's care it seems we will not have a basis for co-operation.

In order to conclude the current experiment I have left some cash with Oliver's sister on the understanding that she has complete discretion as to how she spends it – if necessary in consultation with Oliver's mother. Once this money has run out I shall be keeping my own counsel as to how I spend money on Oliver in future. Since I have never been invited to take part in any of Oliver's Reviews, this is in fact a return to the *status quo*. Please deal directly with Oliver's sister and mother with regard to any outstanding business.

Copies to: Oliver; Oliver's mother; Oliver's sister

Letter. 26th June 2006. To: C. E., Helping Hands Care Agency, Arrow House 8 & 9 Church Street, Alcester, Warwicks B49 5AJ

Dear Ms E.

Re: Oliver Medhurst of 8 Prophets Close, Batchley, Redditch, Worcs B97 4SD

Thankyou for allowing me to see you last Friday 23rd June in order to express some concerns about aspects of my son Oliver's care. Thankyou also for your commitment to making appropriate changes in personnel from today.

I hope that as a result of our shared concern Oliver's feeding regime will be reviewed and renewed. This is because Oliver's optimal weight needs to be maintained in order to prevent the rapid loss which can come about because of calories being constantly burned by contractures and spasms. If Oliver loses weight then there is no doubt in my mind (from more than two decades of observation) that he will experience skin problems, not the least of these being pressure sores. Oliver enjoys his food: it is an important component of his quality of life. Because of his limited range of mastication, feeding him may prove to be tedious, but well worth the effort. It is important that the texture of food is not broken down (ie. mashed); the corollary of this is that the food should be well sauced and lubricated with drinks. If bulk is increased, as it needs to be, then Oliver is likely to suffer from constipation. Fresh fruit and vegetables are therefore an important part of his diet.

I hope also that increased attention will be paid to Oliver's personal hygiene. There is absolutely no reason why he should smell of stale urine, or that his continence aid should be exposed, or that his oral hygiene should be neglected, or that he should be unshaven or otherwise unkempt. This is a dignity issue, and important for Oliver's self-esteem whether he has visitors or not.

I appreciate that Oliver's seating arrangements are problematical. Having purchased an adjustable armchair and a vibrating cushion I am naturally disappointed that these have never (to my knowledge) been used. Perhaps now is the time to consider installing a hoist rail in Oliver's sitting room so that he can be transferred between a range of seating arrangements. It is simply not acceptable to assume that pressure-sores are inevitable; the present situation cannot be allowed to continue. The pain caused by these sores is making Oliver's life miserable. On the other hand, leaving Oliver for long periods on his bed is a massive inroad into his quality of life.

The latter issue raises the question of the role of Oliver's supplementary care in assisting with his transfer by hoist. It is too easy to assert that "Oliver wants to sleep" thus leaving personnel free to pursue other agendas – including, as happened on Thursday 22nd June, leaving Oliver alone in the house. Also, I feel that that visiting carers should be counselled against any attempt to rush their assistance in order to free up time for themselves. For example, when I was spending New Year's Eve with my son a carer marched in at 8.30 p.m. and demanded that Oliver be put to bed immediately – no doubt so that she could

get home early for her own enjoyment of the festivities. If staff are being paid by time rather than by task, this is completely unacceptable.

Above all, it is imperative that, in order to facilitate Oliver's communication, carers maintain a constant interrogatory dialogue with him concerning his situation throughout the day. I personally would not wish to undergo once more the anguish of seeing my son squirm in pain while an otherwise uncommunicative carer spends time talking to a friend on her mobile phone, or smell my son's stale urine while a carer reclines with her feet up watching T.V., or watch a carer cook a substantial meal for her own personal consumption while my son is complaining of hunger. All of these grotesque situations can be avoided by Oliver's carer asking him about his needs on a frequent basis and allowing him to use his "Yes/No" code with ease and effectiveness.

"Hope springs eternal" I hope that on my next visit to Oliver in the near future all of these issues will be seen to be addressed, or begun to be addressed, so that any unpleasant repercussions can be avoided.

Copies to: Dr T. L. (Oliver's G.P.); Mrs S. G. W. (Oliver's Social Worker); Mrs Rebekah Hillman (Oliver's Sister); Mrs Jacqui Medhurst (Oliver's Mother)



APPENDIX

FIGHTING BACK

The Headstart for Oliver Programme (H.O.P.E.)

Published and privately circulated by P. & J. A. Medhurst, 42a Hobson Road,
Leicester. 1984. © Phillip and Jacqueline Medhurst

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FOREWORD. An extract from a leaflet published in August 1983 to promote 'The Oliver Medhurst Birthday Appeal'.

Who is Oliver? In August 1982 Oliver Medhurst was a normal eight-year-old boy looking forward to his ninth birthday, and enjoying the summer holiday. Then disaster struck, and a month later Oliver spent his birthday in a deep coma. Every parent's nightmare had come true. On his way back home from the corner shop Oliver ran out into the road at a pelican crossing and was struck head-on by a car. Witnesses say the driver was not to blame. His parents dashed to the scene to find their son gasping for life. The family was rushed to the Infirmary where it was found that, besides breaking both his legs, Oliver had sustained a serious head injury. During the following weeks in Intensive Care the staff at Leicester Royal Infirmary were brilliantly successful in their struggle to save his life, but could not prevent permanent brain-damage. Surgery at Leicester and later at Derby helped to minimise it, but no-one could be certain how long the coma would last. Three months later, as parents and friends lived through an agony of doubt and fear at his bedside, Oliver began to emerge from his twilight world. But his problems were only just beginning.

The Challenge. Thanks to the constant and devoted care of hospital staff and friends Oliver began to return to the world he had so nearly left for ever. Moments of joy relieved the seemingly unending darkness - like when a visiting police-dog jumped on his bed, barked, and Oliver opened his eyes wide in boyish wonder; or when the shared reminiscences of his mum and dad were acknowledged by a smile - the first they had seen for months. From that moment on, his parents knew that any attempt at stimulation, any contact with the real world, any therapy - no matter how unusual - was worthwhile. As friends prayed throughout the County, their prayers seemed to be being answered. But it also became clear that God had set a task for everyone who cared - a task that demanded all the skill and patience of a midwife at a unique rebirth.

What makes Oliver special? Even when Oliver had "woken up", it was clear that he could not move or talk. In the early stages he could not even swallow. Gradually, he learned to take, chew and swallow solid food. Painstakingly he developed movement in his head and eyes. It became apparent that his left side was more affected than his right - as though he had suffered a giant "stroke". With the strength and determination that only a child has, his struggle to move an arm or a finger continues - every week a millimetre more. He refuses to be "written off". Most surprisingly of all, it has become obvious that Oliver understands everything that is said to him. He listens to stories. He enjoys music. He answers "Yes" by looking up and "No" by turning his head. He cries when something isn't "fair". He laughs at jokes. We thank God that his sense of humour is intact. The "old" Oliver is still very much with us. He still has the same likes and dislikes. He can still be naughty by refusing to eat his dinner, still win hearts by his melting smile and rolling eyes. Oliver is still a person. Like a secret treasure in a broken but salvaged box his personality is still there to be cherished. But we are left with a tantalising question which only you can

help us to answer. How much progress can Oliver make before the vigour of childhood leaves him? And what sacrifices can we demand of the community at large to give Oliver that boost he now so urgently needs? Can you help us face this challenge?

INTRODUCTION

The Basis of Decisions

Multiply-handicapped children like Oliver do not belong to a different sub-species. The same educational criteria apply to them as to 'normal' human offspring. In the education of any child, the aim is to place before him a range of opportunities which will enable him to explore and develop his latent potential. It is a "leading out" (Latin *educare*). If a child is not to be educated for failure, it is necessary for the teacher to be at least one step ahead: to establish realistic goals related to the springs of the pupil's motivation, in the hope - and in the initial stages it is hope rather than certainty - that the young person will progress towards them. To adopt a static approach, in which it is automatically concluded that progress cannot be made to a further stage and the handicapped child needs merely to be occupied or entertained, is a betrayal of the most fundamental of educational principles.

The same criteria apply to therapeutic activity. There is a sense in which no human being is completely "whole". Yet therapy aims to lead the patient to wholeness. This is the essence of the healing art (Old English *hale*: "whole"). Once again, if the patient is to be dealt with rather than just the disability, the therapist must establish realistic goals related to the patient's optimum potential quality of life. To pursue a mere holding operation, in which it is concluded that the patient is simply a disordered body-mechanism whose condition can at best be prevented from deteriorating, and whose needs as a human being are confined to being kept "comfortable", is likewise a betrayal of the most fundamental of therapeutic principles. Even within the narrow parameters of orthodox medicine, such an approach to the management of traumatic brain-injury is medically unsound.

What every professional involved in "very special" education should be aiming for cannot be summarised too easily in a simple phrase. Because our expertise as Oliver's parents lies primarily in the educational field, we have tended to use the term "curative education". Had our expertise resided primarily in the medical field, we might have chosen the term "holistic therapy". Both amount to the same general approach.

For those involved in the assessment and statement of Oliver's needs within the terms of the 1981 Education Act and the consequent allocation of resources, financial considerations may be uppermost. In the present economic climate the setting of realistic goals - related to the "realities" of the child's needs rather than the "realities" of financial constraints - may be distorted by considerations extraneous to education and therapy. Decision-makers in both the health and the education services may seek to establish a pessimistic prognosis, thereby implying that the further investment of resources is futile. On the other hand they may proffer a glib, over-optimistic prognosis in order to justify a "wait-and-see" policy in which the pupil is expected to demonstrate ability and make progress in a vacuum. We have known the same professionals to veer between both stances in accordance with the demands being made upon their service. It is particularly unnerving - when so much is at stake - to encounter

an administrator who has so lost sight of his or her priorities in the implementation of sound therapeutic or educational policy that the process has become unconscious.

The priorities of politicians involved in the formulation of policy and the allocation of macro-resources may also fall victim to false values. Those who would seek to sell our son's birth-right of human fulfilment for a mess of cost-cutting should understand that if education and therapy are costly, ignorance and illness are immeasurably more expensive. Cost must be measured in human as well as financial terms. The creative solutions are less expensive in the long run. A full programme of education and therapy is an investment in Oliver's future independence. Any measure of progress towards this is a long-term money-saver.

Politicians, professionals and administrators all need to be reminded that myopia induced by expediency may place on the fragile shoulders of a handicapped child struggling towards independent maturity the burden of their own inadequate perceptions. In view of these important considerations we have outlined a programme which sets realistic goals for Oliver and describes the means to achieve them. We have not balked at our responsibility for his future. We solemnly anathematise any attempt, conscious or unconscious, to undermine our sacred trust as we seek to deploy all available resources towards the realisation of our child's human potential. We invoke our son's unqualified right to be both accepted and welcomed as a full member of our community. In this sense, our proposals are not simply a counsel of amateurs; they are a challenge to the professionals.

Planning a Programme

This paper as a whole consists of an account of the resources, in terms of personnel, time and equipment, which Oliver needs if he is to make significant progress towards independence. But such resources in themselves are of limited use unless they are part of a co-ordinated strategy, an integrated 'package' in which the aims are clear and the goals precise. It is therefore essential that the Schools Psychological Service construct a programme of precision-teaching for each core area of the curriculum, including detailed task-analysis, the design of appropriate diagnostic probes, the setting of realistic goals within a continuum of genuine progress, and the establishment of daily monitoring procedures. There should be an ongoing reassessment of the programme at least once a term with the necessary adjustment of goals on the basis of this precise monitoring. Such a programme would involve close liaison and frequent consultation with teaching staff – and, indeed, their support, since monitoring would have to be conducted by them. Such a programme should ultimately cover all of the core areas discussed in this paper. But developing the means whereby Oliver can move as swiftly as possible towards the development of a channel of communication is a matter of the utmost urgency. Ian Andrews, an interfacing expert, has commented: “In view of the potential for Oliver's development, it would appear important to establish a proper procedure to monitor his progress. This would require a regular programme of measurement and assessment to record the nature and extent of his progress. Factors which would warrant such attention are:

1. Ranges of movement
2. Strength

3. Precise assessment of capabilities
4. Determination of perceptual sensitivities
5. Recording his communication capabilities.”

The development of Oliver's ability to communicate, then, should be the overriding aim of the co-ordinated strategy. But Oliver must have shared experiences to communicate. The role, therefore, of the “peripheral” curriculum should not be underestimated. Wherever possible, reinforcing links should be forged which undergird both the core and peripheral curriculum, so that the aptitudes developed in basic skills training sessions can be applied at a level meaningful to Oliver in an experiential setting. An example of this is the relationship between communication skills, reading, and practical activities. Blissymbol vocabulary acquired in training with the speech therapist (see CORE AREA 3 - STIMULATION: *Language*) should be transferred to other contexts, with, for instance, Blissymbol stamps being applied to reading-books which cover topics within Oliver's home or school experience, or sheets of symbols generated by the 'Blissboard' computer-program via a printer (see CORE AREA 5 - COMMUNICATION: *Equipment and Materials*) being used as a basis for discussion or to label items in cookery, or providing the design-motives in art and craft.

An Example of Precision-Teaching

The curriculum-model which has formed a rough basis for this entire document is the one outlined by J.W.Murphy, Deputy Headmistress of Oakwood School, Walsall. (“Developing Programmes for Multiply-Handicapped Children - A Curriculum Model” in “Teaching the Multiply Handicapped” Walsall Education Department. 1980.) This outlines six areas for a core curriculum:

1. Basic Self-Help Skills
2. Mobility through Physiotherapy
3. Stimulation
4. Play
5. Communication
6. Environmental Control

The breaking-down of each area - in the initial process of task-analysis - into precise steps towards the achievement of each target is illustrated by Murphy, and provides an excellent example of the way in which a programme of precision-teaching could be refined in ways helpful to Oliver. The following is a paraphrasis of an example pertinent to our overriding concern for his communication skills (See CORE AREA 5 - COMMUNICATION: *Equipment and Materials* for a description of the equipment referred to.)

First Refinement

Core Area: Communication

Components:

Communication Board

Symbol Board

Fist-Pointing

Typewriter

Eye-Pointing

Comprehension

Social Vocabulary

Expression

Second Refinement

Components: Communication Board

Targets:

1. Given a switch and a pointer-board with pictures the child can start and stop the pointer when given either of the commands “start the pointer”, “stop the pointer” on five consecutive trials. (The pictures should be close together so that the pointer always stops on a picture.)
2. Given a point-board divided into eight equal segments and given the verbal command “stop the pointer here” (teacher pointing) the child can start the pointer and stop it in the correct board segment. The position of the relevant board-segment varied randomly between tasks, on ten consecutive trials over five days.
3. Given board and switch the child can start pointer moving and keep it moving for one complete sweep of the board on five consecutive trials over three days.

Third Refinement

Communication Board: Target 2

Steps:

(Materials: three sets of pictures:-dog/kennel; cat/basket; car/garage. The first picture in group of two attached to the pointer. The other picture on the board.

1. Kennel fixed at 12 o'clock on the board and the pointer with the dog at 9 o'clock. The child will make the pointer move in a continuous movement on verbal command 'take the dog to the kennel'.
2. Kennel fixed at 12 o'clock on the board and the pointer with the dog at 6 o'clock. Then as Step 1.
3. Kennel fixed at 12 o'clock on the board and the pointer with the dog at 3 o'clock. Then as Step 1.
4. Kennel fixed at 12 o'clock on the board and the pointer with the dog at 1 o'clock. Then as Step 1.

Such a procedure, suitably adapted, should be applied with Oliver in all areas of the core curriculum. In this particular instance, since we are dealing with a child who has a relatively high level of cognition, Blissymbols or even words could be used in place of pictures provided that he was suitably briefed before the exercise. But the principle remains the same. Murphy comments: “If we are to teach the M.S.H. child anything at all we must ensure that we ourselves can define exactly what the child has to do, and define it in such a way that the child will always succeed and will progress easily from item to item.”

The Use of Equipment

For many readers some of the high-technology equipment described later on in this paper may appear to be a series of strange and elaborate “gimmicks” which may appear to be more expensive and complicated than they are worth. The area of communication-aids and computer-assisted learning is a rapidly

expanding one. While the particular products mentioned may not be the most appropriate as they are displaced by new items, we hold such equipment to be as essential to Oliver's education as writing materials and text-books to a 'normal' child. It is necessary to develop an even broader perspective. To reach an understanding of their fundamental importance we should appreciate our own dependence, as 'normal' adults, on tools to improve the quality of our life.

We may be able to use our hands, but the use of say, a hammer to extend these limits brings about a radical qualitative change to our environment. Even if we have the use of our legs, the ability to extend or replace their function by that ingenious device known as the "wheel" has not only facilitated mobility for the handicapped: it has had an incalculable effect on the quality of human civilisation. The extension of the ear and vocal chords by use of the telephone can overcome more than physical barriers. Perhaps the greatest breakthrough in the evolution of social organisation has been the extension of speech and memory by the invention of writing, and it is no wonder that so much emphasis is placed upon it in our education system. And yet even a century ago the mobilisation of society's resources towards the universal acquisition of this skill would have seemed impracticable. The importance of computer technology to the quality of our lives has yet to be quantified. Applications purveyed to the mass market seem trivial – "space invaders" in more than one sense. For the handicapped, however, microcomputers have been described as "intellectual amplifiers" and "information prostheses". However we describe their function, to the victim of cerebral impairment, the opportunities of brain extension offered by technology within the new discipline of Augmentative and Alternative Communication are crucial to their personal development.

CORE AREA 1 - BASIC SELF-HELP SKILLS

Feeding

Oliver can now swallow. He currently experiences some difficulty in mastication owing to some impairment in the lateral movement of his jaws. While some improvement may be expected as a result of facial massage and other exercises related to speech therapy, motivation is an important factor. It is important that Oliver should be allowed to express preference with regard to food, and that his diet should be as varied as possible. The texture of food should not be obscured by unnecessary mashing in order to speed up feeding. The best way to assist his digestion is by the use of sauces which stimulate and supplement salivation and by frequent drinks. Oliver should be allowed to eat extensively at will between meals in line with the eating habits of "normal" children of his age. Particular attention should be paid to oral hygiene, not only because of dental considerations, but also to avoid the de-sensitisation of his sense of taste.

Three considerations should be uppermost when planning a feeding programme:

1. Good food is an important element in Oliver's quality of life. Eating should be a pleasurable experience.
2. Improvement in the function of oral musculature brought about by eating will improve the quality and range of Oliver's vocalisation.

3. The quality of meals should compensate for the loss of appetite which is the inevitable result of limited physical activity, and avoid the debilitating weight loss and lethargy consequent upon malnourishment - an all too common phenomenon amongst institutionalised patients.

If Oliver is eating well and looks forward to meals, there is every reason to suppose that he will wish to assist feeding by signalling hunger and re-establishing relevant motor patterns. He has already demonstrated an ability to bring his hand and mouth together when hungry. Such actions will be encouraged if food offers a genuine, pleasurable reward for effort.

Toileting

Oliver has shown himself to be capable of exercising relatively advanced musculature control when there is sufficient reward incentive in terms of pleasure or enhanced self-esteem, and when he feels confident and secure about the context - in other words, 'at home'. Very complex mental processes are at work here, and we are faced with a 'grey area' between voluntary and involuntary movement. A great deal of patience and sensitivity is required on the part of the teacher or therapist in encouraging control, and effort should be directed at establishing a congenial environment for progress bearing in mind emotional, psychological and social factors as well as Oliver's own aspirations as a child.

Until recently Oliver was doubly incontinent. By consistently and painstakingly applying the principles outlined above over a period of several weeks his mother has succeeded in bringing about urinary continence. The same effort needs to be applied to bowel movement as Oliver achieves more regular habits of feeding and digestion. Given the more embarrassing nature of solid excrement and the more complicated mechanics of expulsion and disposal, considerable sensitivity needs to be exercised. Physical comfort during toileting is also of paramount importance if he is not to be "put off". Furthermore, if Oliver is not to be desensitised to the social aspects of toileting, and if his self-esteem is not to be undermined by the reactions of others, the accoutrements relating to this function should be removed efficiently to the appropriate place of storage or disposal, and inappropriate persons - such as strangers or even females familiar to Oliver - should not be involved in the logistics of toileting. Such considerations may seem trivial, but the impression left by the sight of a transparent bag of soiled napkins left in the social area of an institution visited by us has proved indelible. It spoke volumes about that institution's attitude to the inmates. As well as clear behavioural objectives, comfort and privacy should be paramount considerations if Oliver is to make progress. This entails a considerable amount of work for which there are few short cuts.

Dressing

Oliver can not actively assist in dressing. He should, however, be encouraged to help passively by the drawing of his attention to muscular tension which hinders the process. Dressing itself offers an opportunity to stretch muscles in a context which Oliver accepts as necessary, and a great deal of the tension precipitated by expectation of a "passive movement" session does not occur. For this reason we do not wholeheartedly approve of labour-saving adapted garments unless they happen to be in tune with current fashion (such as track suits). It is essential that Oliver's clothes should be fashionable, be arranged in

order to “hang” naturally, and any soiling should be swiftly and scrupulously removed. His appearance is fundamental to his self-esteem; his self-esteem is fundamental to his motivation; his motivation is fundamental to his progress.

Bathing

Oliver should be taught the importance of hygiene. As in the case of toileting, however, if we are to win Oliver's co-operation washing should be a pleasurable experience. Indeed, it is necessary for those assisting him to appreciate the positive opportunities offered by the necessary ablutions. The temperature of the water, hot or cold, applied in washing can be used as a means of stimulation or relaxation. Drying can provide a stimulating massage aiding circulation. Use of aromatic toiletries can provide Oliver with some pleasure and stimulate his sense of smell. (The use of an array of bottled aromas proved invaluable in reviving Oliver from his coma.) Bathing should not therefore be regarded as a chore to be rushed, but as an event to be savoured, and wherever possible should be concluded with an oil or lotion massage. Similarly, bathing in a pool may be preceded or concluded with a sauna which will relax him and enable him to derive the maximum benefit from hydrotherapy.

Choice of bathing equipment needs to be given careful consideration. The shower can provide occasional stimulation; it should not be employed as a convenient expedient in a mere 'hosing-down'. A bath is to be preferred since it provides opportunities for leisurely play and variation of posture. In this respect the Parker Bath is useful since it reduces the risks associated with a very dependent patient in water, thus facilitating play. A “jacuzzi” or whirlpool-bath has obvious benefits for the paralysed child. A device marketed under the brand-name of “Relaxabubble” extends a similar effect into an ordinary bath.

Once again, it is necessary to emphasise that what for a 'normal' person may be self-indulgent luxury may be for the sensorily-deprived a means of providing social interaction and that shared experience from which the desire to communicate springs. This is the peripheral curriculum in the broadest sense.

CORE AREA 2 – PHYSIOTHERAPY

Gross Body Movements

While most of Oliver's movements (excepting, perhaps, those in the right hand) are not entirely voluntary, neither are they always entirely involuntary. He can undertake major movement when he wishes to draw attention to himself. He can control equipment such as a tape-recorder or slide-projector by use of a micro-switch when the end-result is interesting to him or adds to his peer-group status. Emotional, psychological and social factors have a considerable influence on his performance. (See CORE AREA 1 – BASIC SELF-HELP SKILLS: *Toileting*).

So-called “spasm” – a term which we consider to be totally misleading – should not be regarded simply as a neuro-physical problem within a body-mechanism which is entirely out of control. The phenomenon appears in certain identifiable contexts as the result of Oliver's emotional condition. For example, when he is hungry his unease leads to tension in the abdominal muscles causing him to “flop” forwards-so-called 'adductive spasm'. Similarly, when he is anxious about an impending event his right leg may straighten and

his foot turn inwards. Both pathological reactions are undoubtedly exacerbated by his inability to communicate his anxieties effectively. Use of muscle-relaxant drugs such as Baclofen or corrective implements such as callipers should be seen in perspective as convenient short-cuts to control of the body-mechanism by external means, and a supplement to, rather than substitution for, daily physiotherapy. A normal growing child not only engages in a great deal of physical activity, he develops skills by monitoring his own performance. This monitoring is sometimes explicit in children's games, such as skipping or hopscotch or 'snobs', or in popular sports. Oliver's inability to participate in such activities, and the effect of this on his growing physique, must be compensated for by an ambitious and very labour-intensive programme of physiotherapy.

But the challenge to the health service consists not only in providing adequate staffing, but also in staff taking account of Oliver's advanced cognition and sentience. He is capable of monitoring what is happening to his body and of searching for internal strategies of exercising control. He must help to find solutions from within himself, but education can assist him. This involves both teachers and therapists in

(a) providing verbal (or other available) feedback in the form of observations to Oliver about what is happening to his body;

(b) undertaking an analysis of the context in which such changes occur;

(c) suggesting strategies for the remediation of such changes by Oliver himself.

Simple examples are as follows:

Feedback: "Oliver, you're getting all tense. You're sticking your leg out."

Analysis: "You always do that when you're worried about something. Is it because you're going to the dentist this afternoon?"

Remediation: "For goodness sake relax. It's only for a check-up. Getting tense will only make you feel worse".

This is a very simple example of the dialogue which would accompany physiotherapy (in this case, gentle manipulation of the affected leg) in the context of a continuous process of holistic therapy or curative education which treats Oliver as a complete psycho-somatic entity.

The insights inherent in this approach can be refined into more precise educational strategies: *visual feedback* can be provided by video and mirrors; *aural feedback* can be provided by attaching mercury switches which activate buzzers; *tactile feedback* can be provided by vibrators. The use of EMG signals in providing feedback should not be discounted. *Analysis* can take the form of one-to-one discussion of the day's programme or discussion at potentially stressful periods such as before mealtimes, visits, or physiotherapy sessions. *Auto-remediation* can be facilitated by changing Oliver's perspective, either physically by altering his posture or mentally by humour.

These approaches may overlap. The educative part, for example, of a hydrotherapy session might run as follows: "Can you see, Oliver, how when we move your head backwards and forwards your body goes up and down?"

(Demonstrate). You're not floating very well now because you're all tense. Is it because the water isn't very warm? (Elicit answer). Is it because you think I'm going to let you sink? (Elicit answer). I'm going to pull you through the water now. You won't get a good ride if you don't relax."

Such an exercise is educative as well as therapeutic: it is exercising Oliver's mind as well as his body.

Clearly, physiotherapy or hydrotherapy which simply manipulates the patient without adequate explanation can have counter-therapeutic effects by unconsciously emphasising his helplessness, and by rendering the patient suspicious, anxious, and therefore physically tense. A valid approach needs a frequent session of significant duration. Whether conducted by a teacher or by a physiotherapist we would envisage a daily session of an hour's duration, with the therapist bearing in mind that language and mental interaction is a fundamental part of the process.

Sitting and Standing.

Oliver's position needs to be changed as often as is conveniently possible between seated, prone and supine. Since he is growing at a normal rate we need to take maximum advantage of his current manageability. In view of his scoliotic condition perpetual vigilance needs to be maintained to keep his pelvis and torso correctly aligned, whatever his overall position. While moulded seats and vacuum-cushions can maintain an acceptable posture, a chair needs to be supplied which is mildly corrective if use of a restrictive body-jacket is to be forestalled.

Such a seating arrangement is particularly important for when Oliver is working. He needs to be placed in a position which is clearly workmanlike, and which maintains his posture steady while he concentrates on the task in hand. If his overall posture is constant, it leaves the way open for fine adjustment in the limbs he is utilising. Thus, for example, his head needs to be steadied in order to help him fine-tune his gaze and apply consistent pressure to a chin-switch. Similarly, since other muscles may react to a neural message sent by Oliver to his hands, switches in this area need to be very carefully placed; a constant posture will assist careful experimentation. Needless to say, any chair needs a detachable and adjustable tray as a working surface.

A chair therefore needs to be provided with thoracic and pelvic pads and a fully-adjustable head-support. Thus Oliver's scoliosis could be controlled by the use of bi-lateral pelvic pads, with the extension of the pad upwards on the side of the convex lumbar spine, and using just one thoracic pad on the side of the convex thorax. This would help to straighten the spine and improve stability of the trunk which in turn will improve the sitting posture. Head supports need to be provided which are fully adjustable for height and width, and a nape-of-neck support needs to be incorporated. A tilting mechanism would add flexibility, facilitating adjustment to the task in hand or countering the effects on Oliver's posture of gravity - while keeping his corrected posture constant.

All the necessary modifications described above can be supplied by The Spastics Society for application to the Avon range of wheelchairs. Corrective pressure to Oliver's feet and lower-limb joints can only be effectively applied by maintaining him in a standing position. The use of a prone-table has the added advantages of improving Oliver's body-conscious-ness, developing his head

control, and may open possibilities – perhaps through the use of slings – in the utilisation of movement from the shoulder or elbow. It will improve his blood-circulation. Finally, a change of physical perspective will add depth to his perception of his everyday environment.

CORE AREA 3 – STIMULATION

Language

Even within the context of a Special School children who cannot talk represent a special minority. Their handicap strikes at the very roots of the educational process. Clearly, non-verbal children are vulnerable to bad educational practice since they do not have the ability to make obvious protest against an unstimulating environment. Furthermore, since both formal and informal assessments of intelligence tend to be based on speech, it is almost automatically concluded – often by people who should know better – that such children have poor educational potential.

In the normal classroom situation non-vocal children may be neglected by the hard-pressed teacher. There may, therefore, be a case for limited withdrawal of such pupils. Such a group, however, should not be a negative way of dealing with an educational “problem” – the classic “sink” group. Stimulation provided by talking peers should only be temporarily removed in exchange for a genuine intensive language-enrichment programme in which a teacher's full creativity is made available to a smaller group of pupils. Oliver's speech therapist has initiated the use of Blissymbols in her weekly session. If Blissymbols are to serve as his main expressive medium for the foreseeable future the use of the system must be carried over into the school curriculum and into social contexts. A withdrawal-group provides the opportunity for an intensive application of the system through specially-adapted materials and equipment. Games, in particular, are an excellent way of extending vocabulary and encouraging social interaction. A special classroom-area reserved for the group should be decorated with stimulus-material using Blissymbols. Withdrawal sessions may provide a workshop in which the system can be applied to subjects taught in 'normal' class time.

Both the Local Authority and the Speech Therapy Department should face the challenge by providing special materials and preparation-time for the teacher involved. If a Bliss-trained teacher is not available then daily speech therapy must be provided.

Preparation of Blissymbolics materials is extremely time-consuming. Commercially-produced materials such as stamps and flashcards can lighten the load considerably, as can print-outs from Blissymbolics computer-software. For example. Gait word-building blends can be adapted by sticking Blissymbol stamps onto the plain half of the tablets. These then have the dual function of providing clues in the word-completion exercise and of encouraging symbol-acquisition through the matching of picture and symbol. In Oliver's case, while it requires manipulation by the teacher presenting him with alternatives and eliciting a Yes/No response, it develops his residual knowledge of phonics while encouraging use of the “new” semantography. In the same way, appropriate books (with simple text but with pictures and themes at the right age-level) can be dismembered and reconstituted as “zig-zag” books for Oliver to

browse without having to turn pages, with Blissymbol stamps applied to the illustrations.

Talking machines can be a fertile source of language stimulation. Unfortunately, machines such as Texas Instruments "Touch and Tell" or "Vocaid" or the Bell and Howell 'Language Master' are not usable without a fairly advanced degree of manipulatory skill. It may be that the newly-developed "Convaid", which is similar to "Vocaid" but with a greater range, may be usable at some point in the future since it has the capacity to be adapted to a double-switch input controlling scanning LED's. Using any of these as a teacher-controlled resource at the present moment in time would, of course, be under-use of expensive equipment. Oliver can, however, control a tape-recorder. He could, therefore, make use of a Ricoh "Synchrofax" machine. This displays a hand-written overlay. The reverse side of the sheet allows for magnetic recording of up to four minutes of spoken material. Otherwise, the controls are not unlike those of a cassette tape-recorder. In Oliver's case, this machine would effect a happy compromise between pupil and teacher-control. Blissymbols could be drawn onto the overlay. The teacher's voice could record the meanings. Oliver himself could control the rate of play.

Talking machines are particularly appropriate to Oliver's needs in view of his excellent hearing and aural comprehension. In view of his vision problems, however, language development material which offers a strong visual stimulus is at a premium. "Pop-up" books, while having plenty of visual impact, do not necessarily draw Oliver's attention to text. In this respect the slide-set 'Say It with Symbols', produced jointly by the Blissymbolics Communication Foundation and the Film Board of Canada (1976) is ideal. It has the added advantage of tackling the problem of a vocabulary extension strategy based on other than phonic considerations (as is the case with most standard vocabulary lists.) A sequence of graded vocabulary is incorporated within the total scheme, while component slide-sets may be used frame by frame or in a narrative format.

Sensory Stimulation

The importance of stimulation in motivating a brain injured child towards progress first became apparent when Oliver was still comatose and items such as a tape-recorder with earphones and an array of scent bottles became important tools in encouraging Oliver's increasing grasp of the "real" world. Indeed, the use of stereophonic headphones with an audio or video-tape recorder, thereby concentrating the aural stimulus, remains a source of considerable pleasure to Oliver - particularly in view of the fact that these media are his chief substitute for reading, and should be regarded positively as such. Nor should the role of music therapy with a qualified teacher be discounted. In our opinion, it is an essential component of any programme of stimulation.

It should be understood, however, that pleasure is not the main object of stimulation. Understanding and control of the real world is the main goal. This can be analysed into two aims:

1. To provide Oliver with well-defined and pleasurable sensory feedback in response to his attempts to exercise control over his external world, and to order the stimuli which the world of the senses offers to him in such a way as to offer possibilities of control.

2. To allow Oliver, by means that are reassuring rather than threatening, to develop an awareness, through sensory feedback, of the spatial extent and potential capability of his own body, and thereby facilitate creative ordering of his internal world.

With regard to the first aim, Ian Andrews proposed the following: "The first essential is to try to establish the means whereby Oliver can exert control over something. That something must initially be a dominant response which makes it blatantly apparent to Oliver that he has done it. Similarly it must be of such a nature that Oliver is able to control it by himself. Further, the nature of the system must be such that Oliver can be left with the equipment so that he can practise as much and whenever he chooses.

Reward devices which would be best at this first stage are:-

1. A vibrator unit.
2. A sound and light unit.
3. A large train set on a circular track.

These, taken in this order, represent a gradual development of sensitivity to stimuli. The *vibration* can be applied either as a small module inserted in a jumper sleeve, pushed into a supporting strap, or similar. Further the vibrator module can be fitted to an inflatable cushion and can then be used as a vibrating cushion on which Oliver can either be lain or it can be used as a cushion on his chair. The vibration sensation, when it is used as a cushion, can be supplied either to the seat or to the back section. As a reward sensation, it is directly effecting his immediate awareness.

A *sound and light* unit would provide a strong reward which would be located near to Oliver but would be perceived by his eyes and ears rather than by direct body contact. It takes his attention to a larger distance from his inner self. The sound and light source can be moved further from his person so that the extent of his perceptive abilities can be ascertained and probably expanded.

The *train* takes this one stage further and makes the source of the reward of longer term interest. There can be a sense of greater control when driving a train than merely controlling a light. Another aspect which arises naturally with the use of a train is that it begins to present an eye following task with the potential for obvious visuo-motor challenge – that is, to stop the train at a particular position etc."

Mr. Andrews recommends an interface device to add versatility similar to the one already developed by Manchester S.E.M.E.R.C. (see CORE AREA 4 - PLAY: *A Toy Control System*).

The *control unit* which acts as an interface between the elbow switch (and the others) and the reward devices should be as versatile as possible. It is most economical to make maximum use of anything which needs to be in a metal case and requires a power supply. It is therefore appropriate to conceive that this unit will perform the following functions: (1) power the sound-light unit (2) provide whatever facilities prove necessary to control the train (3) give the facilities for the elbow switch. (This allows devices to be switched if the elbow is

bent or straightened by various amounts. Initially only a tiny movement can be asked before it switches and this can be developed as needed.) (4) give control of many devices for selection from a single or multiple switch input.

Most of the functions of this unit can be done by a computer system. Switches are discussed in greater detail elsewhere (CORE AREA 4 -PLAY: *Switches*). With regard to the second broad aim outlined above (Page 20). Mr. Andrews offers the following comments and observations: "During my visit we allowed Oliver to experience the sensation from a small battery-powered vibrator unit. This provoked a distinct interest . . . As a general response it is a very effective way to make apparent to children that something is happening." His speculations regarding the application of such a device provide an interesting complement to the discussion of strategies for auto-remediation in CORE AREA 2 -

PHYSIOTHERAPY: *Gross Body-Movements*. " . . . we have just discovered that by using a more sophisticated electrical drive system, we can achieve a wide range of frequency control and we can now employ such a system to excite particular parts of the arm. Now it is known that muscle systems grow under such conditions and it appears therefore that there may be significant therapeutic benefit from such a vibration device. The use of small electrical nerve stimulators is becoming common in many kinds of situations involving pain control. The potential for use of such devices for making children aware of the nerve systems in their limbs is something we are beginning to explore as it may well complement a vibration therapy system. The two techniques may provide a comprehensive approach to the stimulation and development of limb behaviour."

Clearly, such observations take us to the frontiers of orthodox therapy, and for that reason alone are likely to meet with a great deal of opposition. These proposals are a challenge to the creativity and openness of therapists currently treating Oliver.

Finally, Oliver's vision needs to be mentioned, although the repercussions of his problems in this area *vis-a-vis* the use of a communication aid are discussed elsewhere (CORE AREA 5 - COMMUNICATION: *Problems of Communication; Communication Skills*). In order to develop the optimum use of his vision Oliver needs a training device which mimics the operations of a visual scanning display but which allows extreme simplification of the information to be processed. A matrix of coloured lights reinforced by a note scale would be ideal, particularly if it allowed meaningful elements (symbols in terms of sight and spoken words in terms of sound) to be incorporated within the basic routine as Oliver's skill progressed. To date, we have not seen any such apparatus. In view of this lamentable fact developmental work may have to be commissioned on the basis of readily available technology.

CORE AREA 4 -PLAY

A Toy Control System

Toys can provide the reward incentive necessary to encourage Oliver to develop the skills essential to operating a communication device. In general, when Oliver can achieve so little for himself, enabling him to play is crucial to his motivation towards exercising some degree of control over his world. Oliver's present physical ability to barely operate one switch at a time does not present

a great deal of scope. (Although there is every reason to maintain expectation of natural improvement, he must not be placed in limbo. Oliver, as a person, has needs which must be faced now.) Furthermore, his current inability to cope with rigorous time constraints in processing and referring visual information excludes for the moment any use of commercially available computer games. Both difficulties can be overcome, but there are initial problems.

Obviously, the only toys which Oliver can control are those requiring minimal physical movement and co-ordination: battery-operated devices with remote switches. Since a single switch can generally only initiate a single operation such toys are unlikely to sustain the interest of a child at Oliver's level of cognitive ability. The quality of the reward, however, is not the only factor involved. The appeal of the toy is also related to the amount of effort needed to operate it. If the task of operation is too simple, Oliver will quickly become bored with the toy. If, on the other hand, the amount of effort required to operate the toy outweighs the quality of the reward there will be no incentive to perform the task. Thus toys are needed which offer interesting effects, and the effort needed to operate them needs to be finely graded according to Oliver's developing ability.

The rudiments of such a system were hinted at in the last section (CORE AREA 3 - STIMULATION: *Sensory Stimulation*), but Manchester S.E.M.E.R.C.'s Micro-Active Toy Control system offers the best available opportunity of solving these problems.

To operate the system to its fullest advantage, a wide range of switches need to be developed which terminate in a quarter-inch jack plug. (See next section for switches appropriate to Oliver.) These would then be used to operate any of a wide range of toys, all controlled from a jack socket. The toys may include battery-operated cars, electronic sirens and music boxes, rotating beacons, cassette tape machines, disco lights and so on. With the aid of the Micro Active interface it is possible to interpose a microcomputer between the user's switch and his electrical toy. The interface is constructed with jack-sockets for switch and toy. One program, TOY REPEAT, prompts the teacher to key in the number of switch operations necessary to turn the toy on. Another program, TOY HOLD, controls the amount of time needed to press down a continuous mode switch in order to achieve the reward. In this way, a wide variety of input and stimulus conditions can be combined to present to Oliver an appropriate and rewarding task. The microcomputer element can also provide the teacher with an accurate and detailed record of his performance on the V.D.U. or printer. Such a system (now available through commercial suppliers for B.B.C. or Spectrum) has a built-in task analysis which enables play to be used purposefully towards graded skill acquisition in the context of a programme of precision teaching.

Switches

Switches are of paramount importance to Oliver: for the foreseeable future they will provide him with his only means of active control of his environment and exploration of the world. We have seen the importance of stimulation, but the scope of his development is severely limited as long as he is only a passive recipient of stimuli. Choice is fundamental to his self-esteem, motivation and understanding. This is why it is imperative that his existing ability to express preference through his Yes/No code should be used to the maximum, but this can only take him so far.

For this reason, it is essential to provide Oliver with a *range* of switches. To claim that it is necessary to wait until he has proved competence in a particular operation before a switch can be provided is an absurd proposition. No educationalist would dream of depriving, for example, a “normal” child access to books before it had proved its competence to read. There is no doubt that Oliver can be trained to develop competencies which currently exist only as ill-defined potential. He must be placed in situations which are challenging to him, and which make full use of his undoubted ability to understand the challenge, assess for himself his own degree of competence, and develop, either consciously or unconsciously, strategies to overcome his difficulties. The sense of achievement which comes from mastery of the environment, no matter how limited, is of the essence of education. Any child needs an environment in which there is scope for experimentation in tasks and skills which may - or may not - prove to be self-fulfilling.

For this reason, a range of switches must be made available - linked to appropriate feedback devices - in an experimental “workshop” situation. Before we discuss, however, the lines along which such a workshop might develop, it is necessary to say something about the interfacing process. Despite the fact that interfacing - the selection and installation of a device which allows a person to control an electronic aid - can determine the success or failure of the use of an aid, there seems to be an alarming paucity of reliable advice available. D.H.S.S. assessments tend to be cursory and parsimonious. O.T.'s tend to be “computer-phobic”. Teachers, faced with new developments, are often obliged to improvise with whatever is available. Commercial suppliers - if you know where to find them - lack objectivity. Doctors and consultants can be alarmingly ignorant. Statutory services in this country have a great deal of ground to make up.

Assessment packages have been developed in Canada and the U.S.A. A package being developed at the Ontario Crippled Children's Centre isolates four factors:

1. Residual controlled movement;
2. The choice of (body) site;
3. The choice of interface;
4. The method of placement.

At the Massachusetts Institute of Technology client profiles are based on factors of Reach, Force, Speed and Accuracy. Geb Verburg (“Hooking Up’ to the Computer” in *Communicating Together* Blissymbolics Communication Institute, Vol. 1, No. 3, Summer 1983) identifies some of the questions which we are on the brink of facing with Oliver:

- “—Should one, two, three or more switches be used?
- What are reliable rules of thumb or decision criteria concerning when to use a special interface system?
- When should an interface system be changed?
- How does one anticipate and promote physical and mental development through the choice of an interface system?
- How does one optimally take account of a person's preferences (and a youngster's change in preference when the charm of a special input and/or output system turns into a stigma)?”

Clearly, Oliver's teacher, therapists and care-givers are faced with a daunting task. The sooner it is undertaken the better.

The lines along which a workshop situation might develop has been suggested by Ian Andrews in his capacity as a representative of Queenwood Scientific, a firm which manufactures and adapts switches:

“Switch devices at this first stage must be ones which are within Oliver's capacity, or at least virtually so, right at this moment. The major hurdle to be surmounted if the entire enterprise is to be a success is to convince Oliver from the outset that HE CAN DO SOMETHING. We must give him the confidence that his body has useful ability. From such conviction, confidence can grow and he can develop the ‘want’ to learn more.

“To recommend that several switches be acquired at the start so that he can explore them and identify his initial favourite. He will also discover that one switch is a fall-back for days which are not so good whereas others will give him that bit extra challenge for good days. First stage switches should include a lever switch which is operated from his chin, a small mechanical press switch and possibly an eye switch. During my visit Oliver showed himself able to achieve some measure of success with each of these three switch techniques. 'Stage two would look at abilities which look as if there might be potential. Particular interest would centre on the use of his elbow movement. He already has some ability to move the elbow but not by any large amount. Equally, he has no reason yet to want to do so, so it is unlikely that he will actually make much effort to move the joint . . .

“Vocalisation is another area in which Oliver exhibits some capability and which may very well benefit from directed motivation. For example at this stage it would be possible to provide him with a switch which responds to his voice. Should he make a loud enough sound then the unit would act as a switch and turn on some reward device. There are possibilities for refining the vocal task asked of him with future switch systems. At this stage it would be practicable to give him a simple sound operated switch so that he could develop his voice as a switch activator.”

Because of social considerations it would seem wise to concentrate on areas which might be used by a 'normal' person to operate switches, such as the hands. This may not prove viable, and less usual areas of Oliver's physique should be considered. Even if problems prove intractable here, the scope for development is not closed. In the article mentioned above, Verburg points to other possibilities: “Where none of these overt means of control are applicable, it is possible to reach beneath the skin's surface and draw upon the body's internal signal system. An interface exists that reads electromyographical (EMG) signals, ie. signals that control the muscles, and research is being conducted that uses the electrical activity of the brain to determine what a person is looking at.” Many of the issues and techniques involved in interfacing and other aspects of augmentative and alternative communication are discussed by the American E. Paul Goldenberg in *Special Technology for Special Children - Computers to Serve Communication and Autonomy in the Education of Handicapped Children*, University Park Press, Baltimore, U.S.A. 1979. It should serve as a text-book for all of those seeking to help Oliver, not only because of the information which it contains, but also because of the spirit in which it is written. Goldenberg's discussion of the needs of “Jane” are included in the Appendices to this paper for purposes of comparison with Oliver.

CORE AREA 5 – COMMUNICATION

Problems of Communication

Since Oliver (at the time of writing) cannot indicate effectively with his fist any communication system must be dependent either on eye pointing, or on a mechanism operated by a micro-switch. Oliver has also begun to use a head wand and there is every reason to expect that this capability can be refined with practice. Because of this developing situation any non-mechanical communication aid ideally needs to be multi-purpose in design, capable of being used for eye pointing, head pointing, and as a teacher controlled aid.

Before we discuss any such aid in detail, however, it is necessary to discuss some of the problems which need to be overcome.

Oliver is just beginning to develop some competence with a thumb switch in his right hand, but at this early stage (as discussed in the previous section) a range of switches needs to be provided with appropriate feedback devices which would facilitate a programme of precision teaching. Since, however, any mechanical communication device involves operating a switch in response to a visual stimulus, Oliver's hand-eye co-ordination needs also to be developed.

He is experiencing certain difficulties with his vision. According to his own testimony he cannot see with his right eye, although it is difficult to interpret this. He also appears to experience some difficulty in tracking which may be the result of a slowness in focussing on the temporarily static stimulus. This would correspond to the slowness of movement in other areas. This, of course, may improve as Oliver establishes alternative pathways of voluntary control. On the other hand the problem may be more fundamental than a defect in the neuro-muscular focussing mechanism. He may be suffering from a-centric tunnel vision. This might enable him to see objects clearly *only* when they are moving. (People with normal vision can experience the effect of this by observing a stimulus out of the 'corner' of their eye.)

The practical outcome of the defect is that Oliver appears to require a more than normal time in reading a sentence and may "lose" a moving L.E.D. on a visual scanning display system such as a POSSUM Communicator 16. Since these difficulties hinder his educational progress it is important that we have as much precise information as possible at our disposal. Unfortunately, further information on this problem is not forthcoming. We have found that medical consultants are not above the most primitive prejudices regarding the victims of cerebral damage and with disappointing consistency have automatically assumed that Oliver is incapable of providing reliable information about his own problems. It is therefore a matter of lay speculation as to whether the source of the problem is within the eye-muscles, optic nerve or visual cortex.

Continuing our speculations, it would appear that Oliver's major problem is with tracking. He is capable of seeing any static object in great detail – a die, for example. He is also capable of seeing movement: as was witnessed by his amusement whenever the Communicator 16 was switched to maximum scan rate – which is very fast. He is also capable of interpreting a complex moving stimulus, such as film or television. Some months ago auditory reinforcement was undoubtedly a factor in his comprehension, but now it is obvious that he

can understand visual humour. For example it was quite apparent recently that he was deriving great pleasure from the T.V. screening of a silent film starring Harold Lloyd. Oliver's "problem", then, may reside in his impaired ability to process the information offered by a stimulus which changes its location and is alternatively static and moving.

Oliver needs to be able not only to visually track a "stop-go" stimulus but also to control its movement by means of a switch. Here his problems may be compounded by impairment of the pathways which undertake the referral of information towards correlation. In other words, brain damage may have affected his ability to relate two tasks simultaneously. Thus, presented with the task of both operating a switch and of processing complex visual information, he is unable to do both effectively. It is quite possible, of course, that when Oliver self-consciously attempts to perform such a task he tries to use 'old' now-damaged circuitry which is ineffective. Again, there is every reason to suppose that these problems may be slowly overcome with training. Motivation is clearly a factor in Oliver's progress. Feedback must be unambiguous, entertaining, but with sufficient subtlety to hold his attention. Recently, for example, Oliver appeared to lose interest in using his thumb, particularly when faced with his difficulties in using the Communicator 16. When a new application was found for the device as a die, with locations being selected randomly with the device on the maximum, uncontrollable, scan-rate, Oliver "re-discovered" this particularly movement.

This is Oliver's problem *vis-a-vis* communication in a nutshell. On the one hand, we have a child whose ability to process sensory information and perform simple manipulatory tasks is at pre-school level. On the other hand, we have a child whose grasp of meaning and whose cognition and associative functions are normal. If Oliver's ability to communicate is to develop, these disparate capabilities must be made to converge in a system which is capable of increasing levels of sophistication.

Eye Pointing

In the first instance, an eye pointing programme using Blissymbols should be developed. Once again, we must emphasise the need for any techniques acquired by Oliver to be extended beyond the speech therapy session into the school curriculum. And as in the case of creative play, precision teaching based on realistic task analysis and thorough monitoring must be pursued if the all too frequent drift into a hand to mouth approach is to be avoided.

The programme developed by P. J. Conner at Como School, St. Paul, Minnesota, U.S.A. (in H. Silverman, S. McNaughton, B. Lates: *Handbook of Blissymbolics*, Blissymbolics Communication Institute, Toronto, Canada. 1978), suitably adapted, may form the basis of such an approach, Conner's own summary is as follows:-

- "1. Establish two gross eye-pointing positions (left and right of the vertical midline) which allow for a reliable indication of choice.
2. Establish colour associations (eg. red and green) with the two positions learned.

3. Transfer the two colour-coded eye-pointing responses from the horizontal to the vertical plane.
4. Establish 10 colour-coded eye-pointing positions on a perspex sheet (vertical plane).
5. Develop a 10 symbol, one colour-code eye-pointing communication board.
6. Develop a 10 symbol, two colour-code eye-pointing communication board.
7. Establish 'yes' and 'no' response positions on communication board.
8. Transfer use of two colour-code eye-pointing response to 100 symbol board.
9. Establish 10 number-coded eye-pointing positions on a perspex sheet (vertical plane).
10. Train the child to retain and eye-point to sequences of two or three numbers.
11. Transfer use of number-coded eye-pointing response to 200 symbol-board and/or 400 symbol-board (with symbols numbered consecutively, starting from upper left corner to lower right corner)."

Step 7 in Oliver's case is not essential since he can efficiently indicate "yes" and "no" by a well-established code. Indeed, since teachers and therapists are not always scrupulous in ensuring that Oliver has understood a particular task (partly because of doubts, based exclusively on prejudice, about his level of comprehension), utmost care should be taken to check via the code that Oliver has understood the task before proceeding.

Equipment in the form of an E.T.R.A.N. frame needs to be provided for this mode of communication. Any unit should involve

- (a) No more than two eye-points;
- (b) A large format to facilitate more definite interpretation of eye-movements;
- (c) Interchangeable symbol units to facilitate careful vocabulary extension within the same system;
- (d) A device for developing syntax;
- (e) A vocabulary-extension strategy.

Such a unit could be based on a free-standing triptych with "windows", enabling the teacher or therapist to more readily identify Oliver's eye points. A concave shape would enable the same system to be used with a head-wand. Oliver's use of a head-wand needs to be developed since it requires less concentration on the part of the message recipient than eye pointing. Also, a communication board used with a head wand can be portable in the form of a wheelchair tray. Such a tray – raised, tilted, and with a cut-out for Oliver's torso – needs to be provided.

The problem with both units described above is that of providing for the interchangeability of display items. Systems could be devised which use transparent overlays in acetate, acrylic or P.V.C., or magnetism, or velcro strips. The display items themselves should not present a problem. The time-consuming activity of drawing symbols with a template can be largely

by-passed – except in the case of “personalised” symbols (eg. “Lottie” instead of “dog”) – by the provision of several sets of commercially printed Blissymbol flashcards and stamps (supplied by *Living and Learning*, Duke Street, Wisbech, Cambs.). Such materials can also be given a non-utilitarian application to displays, books and even objects. (See CORE AREA 3 – STIMULATION: *Language*.)

For general teaching a magnetic display board (“Magiboard” – desk-top model) needs to be provided. Teaching can be conducted by drawing directly onto the board with a felt-tip pen or by applying symbols or letters pasted onto magnetic rubber flaps. (Materials prepared for a “Magiboard” can also be used with a magnetic pointer board - see *Equipment and Materials*.) Any *ad hoc* display could then be worked on by Oliver using a head wand or eye pointing.

Communication Skills

Skills developed through procedures described in CORE AREA 4 – PLAY need to be applied to a communication system using switches. Despite his visual and motor difficulties, Oliver needs to be trained in the use of a visual scanning device which preferably uses aural reinforcement, and which can be used in a non-automatic mode. A suitable piece of equipment may have to be commissioned. In the meantime a device using six or ten locations with a bleep facility is manufactured by Geoffrey King Enterprises (54 Chenton Road, Winchester, Hampshire). Equipment and procedures described in previous sections should lead to progress in this area.

Equipment and Materials

The communication device which can perhaps be put to optimal use at this stage of Oliver's development is a mechano-electrical pointer board. Two models are commonly available. The “Telemachus” model, while it can be used horizontally to indicate objects, needs to be disassembled in order to display items behind an acrylic frontage panel. The “Q.E.D.” model is magnetic, thus facilitating use of materials prepared for a desk-top “Magiboard”. The portable model also has a speed control knob varying the rotation of the pointer between 2.5 and 5 revolutions per minute; thus Oliver's mastery of this device could be extended. It is also possible to insert indicator lights at various locations around the circumference, reinforcing the visual stimulus.

In view of Oliver's vision difficulties – perhaps situated, as previously mentioned, in his cerebral sensory-motor referral centres – he will probably need to be coaxed towards hand-eye correlation and co-ordination. He should therefore be briefed on the content of any items placed on the pointer board, perhaps by means of the “Magiboard”, before they are placed in position. Also, initially, he will need auditory feedback as the pointer passes round the board. Since the device does not provide this electronically, it would have to be provided verbally by the teacher. As usual, close monitoring needs to be maintained in order to gradually increase the complexity of the task – including the gradual withdrawal of preliminary briefing and auditory feedback.

Oliver's motor difficulties currently result in problems in releasing a switch, and it may be that the one press/one location movement device described under *Communication Skills* may offer more scope for development in the early stages. It is, however, imperative that some effort be made to develop Oliver's visual tracking ability since most “higher” communication aids for the disabled – most

commonly marketed by POSSUM – rely on this ability. In view of the educational need, the visually simpler scanning mechanism of the pointer board may be the best introduction to an automatic continuous mode.

Once these skills have been acquired we may then think in terms of a patient-operated computerised communication aid accessed via a visual scanning display. There are several such systems on the market, either consisting of a software package enabling a commonly available microcomputer such as the Apple II to be used in this way by means of a cursor-accessed matrix on the V.D.U., or incorporating specialised hardware. An example of the latter is the S.P.O.C. (Speech Output from Computer) package recently developed by Techneg Clwyd Ltd. Incorporating a speech synthesiser, this hardware and software package based on the B.B.C. micro is accessed through a visual display unit which scans 160 locations. These can then be de-coded by the computer to correspond to the Bliss core vocabulary chart. C.E.A.D. (Communication and Environment Aid for the Disabled), also based on the B.B.C., enables the user to manipulate text on the monitor via a single switch input, and incorporates an environmental control system. (See CORE AREA 6 – ENVIRONMENTAL CONTROL.) A fair range of programmes have been written for the B.B.C. for use with a single switch input. Mr. J. M. Leonard of Lickfield, for example, has designed a typing programme (“Autotype”) and some games (“Noughts & Crosses”, “Line of Four”, “Draughts” and “Fox and Geese”) for use in this way. Further details of these devices and materials are provided in the POSTSCRIPT at the end of this paper.

Although a computer can be used at this stage to develop Oliver's basic skills – through use, for example, of the Micro-Active Toy Control Interface – he is clearly some distance away from using such equipment as a direct communication aid. The problems which must be faced are discussed under *Intermediary Systems*. In the interim period, however, there are considerable advantages – not the least being Oliver's habituation to this kind of technology – in using a computer system controlled by the teacher or therapist. When a computer is used in this way, however, it should be observed as a general principle that only software which Oliver may be able to handle at some future stage of development should be used.

A good example of this is the Blissymbolics software written for the Apple II system. “Talking Blissapple”, developed by the Trace Research and Development Centre, U.S.A., enables the teacher to build syntax on a monitor from a chart-based user-vocabulary. Each symbol in the lexicon is numbered or may be ascribed a number, and there is a system for accessing numbers displayed on the screen by means of a single switch controlled cursor. As each symbol is selected Oliver could receive auditory reinforcement via the speech synthesiser and the printer could supply a permanent record of the ground covered. The suite of programs – “Bliss Library”, “Blissboard2” and “Bliss Drills” – developed by the Minnesota Educational Computing Consortium, U.S.A., is parallel to “Talking Blissapple”, but has a refinement which is applicable to Oliver's needs at his present stage of development. As would be expected from software developed from trials within special schools, “Bliss Drills” is an educational programme rather than a straightforward communication programme. Users are invited to match one of a short series of randomly displayed symbols with the “permanently” displayed symbol. Both stimulus and distractors are from a thematic group such as ‘family’, so that meaning related groups are learned. The flash rate of the match sequence can be regulated from one to ten seconds –

while the programme is running, if necessary, by the use of a paddle. Correct matching is rewarded by a "smily face"; incorrect matching by a "sad face". Needless to say, the matching can be done by a single switch. Such a programme answers precisely to Oliver's needs not only by extending Bliss vocabulary but by encouraging simple visual acuity and developing fluency.

Intermediate Systems

One of the most urgent problems facing Oliver and children like him is the leap in expectations of the patient/pupil from a simple device such as the pointer board to a computer based communication aid. Unfortunately, most purveyors of computer-systems for the multiply handicapped skirt around this problem. There are undoubtedly some developments in academic institutions which may never be marketed commercially. South Glamorgan College of H.E., for example, has done some work on visual stimuli. These include a dedicated 8 x 8 array of lights than can be programmed, and programs for shape and colour recognition. Further information is not readily available at this stage, and it is hoped that such initiatives as the organisation of a database at the Newcastle Polytechnic Handicapped Persons' Research Unit will make such expertise more readily available. More readily accessible centres, such as Manchester S.E.M.E.R.C. or Walsall E.D.C., or the Midlands Centre for Neurosurgery and Neurological Research, might be called upon to provide information or expertise which might help Oliver.

A few resources are available commercially. Geoffrey King sells a suite of programmes for the Sinclair Spectrum and ZX-81, one of which, "Doorman", is entirely appropriate to Oliver. A "man" moves very slowly across the screen towards a "door". When he arrives the user is expected to press his switch. Correct timing conjures a "smily face". Success automatically increases the rate of approach, failure automatically decreases the rate. A record of performance appears on the screen. Besides providing Oliver with a task which is entertaining and which he can actually perform, it is an important diagnostic tool providing valuable information towards the use of a visual scanning system. Elfin Systems have also developed software which allows large format symbols to be scanned towards the control of linked appliances.

It is an area which developers are gradually becoming aware of: namely, the educational potential within a computer system to train up the user to increasing levels of complexity. This realisation informs Ian Andrews' description of his own prototype system, the "QuCee": "The ultimate aid for Oliver is undoubtedly some form of computer since it would give him the means to produce a record for communication to others. As yet such a facility is far beyond his compass. What is really required is some system which operates on the basis of reward for simplest action and which can expand in the tiniest of stages upwards by introducing choices and tasks of ever growing complexity. Such a system is now in prototype stage in our laboratory. It is being developed for children with just the requirement of Oliver. Such a system gives the facility of having a computer which is tailored precisely to the exact needs of the child. It can grow with the child from their starting capability of nothing right up to the stage from which they could move on to a more conventional computer."

CORE AREA 6 – ENVIRONMENTAL CONTROL

A Computer-Based Environmental Control System

All of the skills necessary for Oliver to operate an environmental control system, together with the equipment necessary to develop them, have been described at various points in previous sections. The degree of integrated complexity and customised work that such a system entails if it is to meet the specific day-to-day needs of the user within the parameters of his capabilities means not only considerable financial outlay, but also dependence on one supplier. The following extract from a proposal drawn up by Mr. J. H. Taylor of Elfin Systems not only illustrates the equipment involved in a typical system but also gives an insight into the total service that needs to be offered by a supplier to a client who, like Oliver, has developing needs.

“Details of the Elfin Communicator and Environmental Control System proposed for Oliver Medhurst

Hardware (Communicator):

Video Genie EG 3003 microcomputer system with 16K memory and integral cassette player.

Braid speech synthesiser unit.

Green screen computer video display unit.

Three special sets of inputs, one incorporating an electronic switch to harness the small residual movement in Oliver's fingers, one set of head switches, and a light touch thumb switch.

Environmental Controls:

A full environmental control system to give full control over electrical appliances and the family television set. Provision for enhancing the system at a later date to operate electrical toys or to program and operate a microcomputer if Oliver's development is sufficient.

A mains electricity control system operating without control wiring with control signals transmitted through the existing house wiring to receiver units plugged into the 13 amp sockets.

Two receiver units with provision for a further fourteen.

A television control using a remote control adaptor, giving full access to the Teletext service.

Software:

Provision of one duplicate copy of a suitable ELFIN communicator programme, updated free of charge for twelve months to meet Oliver's needs as he progresses.

User Inputs:

Provision of three sets of user inputs as detailed above, selected to suit Oliver's requirements at the time the system is commissioned.

Required additional inputs at a charge based on the costs ruling at the time of supply.

Contact:

Maintenance of positive contact with Oliver free of charge for twelve months from date of commissioning to ensure that the most efficient use is being made of the equipment and of his abilities. Availability of this service after twelve months on a contract basis or a daily cost basis as appropriate.

Guarantee:

Guarantee for twelve months from date of commissioning against mechanical or electrical defects in manufacture in accordance with the consumer's statutory rights, and with no acceptance of liability for consequential loss or faults resulting from abuse or unfair wear and tear.

The system as outlined presents two stark challenges to the statutory authorities. Firstly, to what extent is the Education Services willing or able to provide a comparable system in the school setting so that Oliver's education towards personal independence can begin without further delay? And secondly, to what extent are the D.H.S.S. and the Social Services willing or able to meet their responsibilities in providing a comparable system for home use which takes into account Oliver's age, abilities and potential?

APPENDICES: ALTERNATIVE PERSPECTIVES

APPENDIX 1

Extract from a report sent to Oliver's parents from Mr. Ian. M. Andrews of the Queenwood Institute.

“It is obviously impossible to make any absolute predictions regarding the increase in capability which can be achieved for Oliver. What we do know, however, is that he is making progress since his accident. His age is still within the normal growing and development range and so there is considerable reason to expect him to be able to extend his capabilities beyond their current limitations.

“Oliver is known to have been able to read. Since he still has some visual ability it should be possible to achieve a marriage between him and technology in such a way that he can employ that capability – and probably, with the means to exert his intentions on the concatenation of letters for communication purposes.

“In regard to movement, Oliver has fairly good control of head rotation. This should be exploited as his basic switch facility through head-rotation and chin-lever switches. His arms show some potential for movement, but to what extent that can be developed needs to be established by proper data. A regular measurement programme will soon show up how he is progressing and possibly allow extrapolations which indicate how much further he might be able to go.

“The most important stage of all is the first one. It is essential to get Oliver from a purely passive entity to a person who can and wants to do something. The first emphasis on switches which are within his immediate capability to operate and for use with blatant and pronounced reward devices should induce a desire to exert control. If this can be achieved then we can take Oliver step by step right up to realise his ultimate limitations. If we cannot take these steps Oliver may continue to be unresponsive and will never achieve any measure of independent capability.”

APPENDIX 2

Summary of the views of Oliver's parents compiled by Mr. G. T., Principal Educational Psychologist (Leicestershire).

"Following the severe road traffic accident there have been varying degrees of recovery in Oliver's physical state and functioning level. In this, as in other respects, the parents are keen that there should be a continuous review of progress. In particular they would like more information about Oliver's present visual functioning and future visual capacity. They are keen to know about visual acuity, binocular fusion and the extent and variability of the visual field so that this can be closely related to actual apparatus and teaching techniques.

"Oliver's emotional state will obviously be very crucial to all aspects of his educational needs. His feelings about himself and his condition are obviously highly relevant to his motivation to learn and exchange of information between professional staff and the parents will be vital in this matter.

"Before the accident Oliver was functioning in the cognitive sense as a normal boy with an enquiring and alert mind. The parents now observe that his mind is active and, given the right supportive environment and encouragement, alert. From their observation he is aware of the detailed content of information which reaches him and reacts well to the minor nuances of conversation. In view of misunderstandings which inevitably arise because of his physical condition, the parents particularly believe that one should not make any assumption about Oliver's level of cognitive function apart from the one that he has the capacities of a normal child of his age.

"The issue of communication skills is regarded as being of over-riding consideration and probably the main issue in his needs at present. The best ways of enabling him to communicate as fully as possible need to be urgently explored as there is a great deal of potential which needs to be harnessed to an effective communication system. He is thinking well and has a lot to communicate. The parents are therefore particularly interested in speech therapy and believe that the technique of Blissymbolics seems to be an appropriate approach but they wonder if there may be other techniques which may be equally appropriate. The issue, in the first instance, is the best way of combining Oliver's limited physical control abilities to a communication system capable of sophistication and subtlety. The parents would like electronic learning and communication aids to be provided.

"Physiotherapy is also seen to be very important. Physical exercise is an integral part of his education. Furthermore, if Oliver is to be taught to manipulate the controls of a communication system, then the physiotherapist would need to be involved. It is particularly hoped that physiotherapy would be linked in with the total communication package.

"The parents comment that before his accident Oliver's personality was such that he was not always motivated to learn if he did not think that the situation was right, ie. he could at times have a strong personality in terms of deciding where and when he would make an effort. For instance he appeared to be slow to start talking as an infant, but then did so in comparatively detailed

sentences. The parents therefore feel that it is now possible that he may sometimes be capable of more skills, eg. the return of some simple speech, than he is willing to show.

“The parents believe that education for Oliver should extend beyond term time and that a broader approach needs to be made during long holidays with the probable involvement of Social Services and perhaps volunteers. They have a major interest in the details of the curriculum and have expressed a wish that the Adviser for Special Educational Needs and the Schools Psychological Service be involved in detailed advice.

“As Oliver seems very aware of what is going on his problem is seen as being basically physical unless there is strong evidence to the contrary. They believe that he should be in a school for physically handicapped children and have appreciated the stimulating and lively environment of Ashfield School.

“The parents expect that notification of any form of examination or assessment will be notified to them well in advance and that similarly they are given early notice of case conferences or other opportunities to exchange information with the various professionals concerned.”

APPENDIX 3

Extracts from E. Paul Goldenberg: *Special Technology for Special Children {Computers to Serve Communication and Autonomy in the Education of Handicapped Children}*. University Park Press, Baltimore, U.S.A. 1979.

“Jane is a 13 year old, spastic, cerebral palsied girl whose size and physical development make her appear to be about 9 years of age. Her voluntary movement (arms, legs, and mouth) is extremely restricted in speed, range, accuracy and strength. She cannot sit herself up in bed, dress, feed herself, or control her wheelchair. She has a reflex grasp, but for practical use, she cannot grasp or hold anything. On occasion, she speaks, but she seldom produces more than a high squeak. She has signs for 'yes' and 'no' and, slowly and with great effort, she can point to words on her word board. Within the limitations of her ability to respond, Jane shows that she can read, spell (including reasonable spelling for new words), arrange words in grammatical order, and understand spoken language. Her medical records show disagreement about her mental capability, some diagnosticians claiming she is retarded and others referring to her as a 'bright little girl'.

(Motivation)

“Jane's physical abilities vary considerably from day to day, with motivation apparently a key factor. This is perhaps not very surprising when we consider the payoffs Jane receives for her efforts. The mark of real autonomy depends on what options are open to the individual. For a child whose movements are uncoordinated but stronger than Jane's, showing independence by doing as much as possible without help might be the clearest sign of autonomy. For Jane, however, there is no independence to show. There is nothing of real salience in her life that she can do completely alone, so all of her efforts only service to help the person she is dependent on. Thus, the greatest show of her autonomy, paradoxically, is to do less than she is capable of, to withhold the help that she can give, to use her own dependency to control others. The discrepancies between her best performances and her typical performance are great. Some people make generous allowances, but others say she is obstinate, lazy, or even a deliberate con-artist. The interpretations vary, but the observations are the same; she seems unmotivated and does less than she appears capable of.

“In order to give Jane appropriate care, we must consider both her physical abilities and her psychological state, her motivation. In school she appears not to use her word board unless coerced into it. Being the first to respond 'Tuesday' when asked in class what day yesterday was is not a driving life issue for her. The major problem that she faces is that, if people left her, she could not live at all. For Jane, making a living consists not of academics, but of keeping people nearby who have taken physical care of her and whom she likes. Pointing to 'kiss' or 'thank you' or 'I like you' in the latter context is something she does, apparently quite readily. If one follows the line of thinking still further, it costs Jane effort to communicate, and the returns should be great if we expect her to make the investment. With a sufficiently friendly computer interface she could turn on or off a T.V. at will, drive her own wheelchair, and select from and eventually create her own computer entertainments. The

addition of efficient, useful and satisfying communication to her life may have an avalanche of benefits.

(Educational Effects of Communication Problems)

"The inability to write or to type, even for a child who is able to speak easily, has a grave impact on the child's learning. Although the child can and does constantly learn from what he sees and hears around him, the specific relationship of teacher and student requires that both parties get adequate feedback on their interaction. The child who cannot produce a written response must orally express his comprehension (or lack thereof) of a principle of physics, his impressions of a book, or even his ability to add. Some skills are almost unlearnable in the absence of writing.

"If the non-writing child also cannot speak . . . he is almost totally ruled out of conventional teacher-student relationships. When a teacher can get only a yes/no response, a few crude gestures, and a limited amount of unreliable pointing, there is seldom enough information available to guide the teaching/learning process. Thus, the physically handicapped child, who has already been deprived of much of the incidental 'sandbox learning' (non-school) experiences of the normal child, may lose the chance to learn efficiently even in the classroom for lack of appropriate feedback, regardless of the child's intellectual capacity.'

(Experiential Deprivation)

"What is physically wrong with Jane is her motor handicap, but the secondary problems arising from such severely restricted expressive ability and limited feedback so totally overshadow the 'original' problem that they must be considered the real handicap . . . Conversational behaviour is a highly structured activity that breaks down when one side is not responding normally. People tend to talk to an expressively handicapped child less often, less intelligently, and about a far more limited range of things than they would with a normal child. For Jane to become competent at being a non-vocal, non-ambulatory, non-manipulative adolescent, she must learn to satisfy her needs without text production capabilities (for a common example). Furthermore, her experiences rarely give her much to say. A communication aid provides her only with the modality and not with a reason to communicate. Worse yet, it allows us to be deceived about her capabilities. If she can communicate but does not, or if she can, but does so "defectively", or if she can and we use that modality to test her and she tests poorly, we may (and frequently do) falsely assume her to be intellectually lacking.

"Motoric disability thus eliminates many direct experiences that the child could have. It distorts or destroys many of the vicarious experiences that fluent communication could provide, but even this is not the full extent of the destruction that a severe physical handicap can produce. The child's perceptual development itself may be below that of an able-bodied child. Considerable research suggests that perceptual development depends at least to some extent on perceptual-motor mapping that develops out of observing (and otherwise sensing) one's own co-ordinated activity . . .

'With the flexibility and affordability of off-the-shelf microprocessors, we for the first time have the chance to open up a world of much more normally

experiencing to the severely physically handicapped child, thereby removing many of the handicaps now associated with physical disabilities.

(Motor Skills, Environmental Control and Play)

Research grounded in the belief that physical and mental skills are highly similar has produced some observations that lead to a new understanding of the development and facilitation of physical skills . . . The notion that a complex physical procedure such as juggling can be decomposed into smaller easy-to-learn sub-procedures and can be communicated verbally has a message for the habilitation of Jane and children like her. Locating an object in space and grasping it is a complex procedure. We can see babies practising the "primitives" and sub-procedures which, combined properly, will lead to reaching and grasping.

“What about a child like Jane? Such a child gets inadequate feedback either because she cannot make enough of a movement to get clear visual and proprioceptive information back or because extraneous movement is occurring that makes it difficult for her to determine what part of the feedback is signal and what part noise. Teachers and therapists who have a clear understanding of how physical skills are built and who can provide accurate sensitive feedback may be able to help Jane learn to reach and grasp much the way I could learn to juggle. The fact that reaching and grasping are not 'natural' to her may be no more of a hindrance than the fact that juggling is not natural to me . . .

“As liberating an experience as it is to gain new control of oneself, it must have even greater significance to see that one can immediately use this self-control to have predictable and desired effects on one's environment. Severely physically handicapped persons are prevented not only from writing and feeding themselves, but also from playing, which for normal children is an enormous source of informal learning and one that should be stressed in the design of activities. In order for these children to communicate with the computer, they must perform some voluntary act. By choosing sensitively among the acts that these children perform, we can find acts that allow them the optimal access to the computer and communication, and that help them practice muscular acts that can be the sub-procedures that the child may one day be able to combine into a complex physical act. We are not sugar-coating an exercise to make it fun, but are taking an enjoyable and beneficial activity and adding another free benefit to it. The philosophical distinction, I believe, is important.”

POSTSCRIPT

Hardware, Software and Peripherals suitable for use with a Multiply-Handicapped Child and Compatible with the B.B.C. Microcomputer.

Leicestershire schools are more-or-less committed to the B.B.C. microcomputer system. The following is a list of aids compatible with the B.B.C. which Oliver might be able to use now or at some point in the future.

Interfaces and Communication and Environmental Control Systems with Associated Software.

B.B.C. "Model B" Possum Scanning Computer Control. A light is moved around the indicator panel in order to select the computer function required. This can be controlled by any input switch. Possum Controls Ltd, Middlegreen Road, Langley, Berkshire SL3 6DF. Tel: 0753 79234

M.R.C. Project "Care". The objectives of "Care" are to provide facilities for disabled persons who are unable to use a keyboard by designing and providing input devices they are able to control. The system uses a B.B.C. micro with disc-drive, V.D.U. or printer. A suite of programmes has been developed that can be operated from either on/off contacts or variable signals; also a control unit is provided to link special input devices into the computer. SOFTWARE: programmes for stimulation of interest, assessment of function, education, rehabilitation and communication. W.J. Perkins, The National Institute for Medical Research, Mill Hill, London NW7 1AA. Tel: 01-959 3666

S. P. O. C. Communicator. The "Speech Output from Computer" communication enables non-verbal physically handicapped people to 'talk' to others and to control their environment through the use of a single switch. Multiple inputs can be used by people who can exercise greater control. S.P.O.C. is a custom package which can be tailored to the user's requirements through the use of modular software stored on Hitachi Compact Floppy Disc data cassettes. Running on the B.B.C. micro, it displays onto a monitor or normal T.V. screen. The option is available to replace or supplement the screen with a personal audio output for the visually handicapped. Speech is generated from its own built-in speaker, adjustable for pitch and volume. The voice is built from phonemes, so there is no restriction on vocabulary. The Communicator can also control four external devices simultaneously (with additional hardware). It has four switch inputs and four analogue signal inputs. SOFTWARE: the package comes with full documentation on 3" or 5 1/2" disc. L.A. Thomas, Techneg Clwyd Technics Ltd, The Coach House, Kelsterton Road, Flint, Clwyd CH6 5TH. Tel: 0244 810518/816236.

Selectakey. This provides an alternative input to the B.B.C. computer where the normal keyboard cannot be used. Consisting of 160 switches continuously scanned by internal circuitry, Selectakey interfaces to the computer via a flat ribbon-cable to the user port. It is 'intelligent', informing the computer only when a key is pressed. This makes application software easier to write.

SOFTWARE: A utility software pack on disc or cassette decodes and displays switch selections. An advanced software pack decodes the switches according to the Bliss Core Vocabulary Chart. L.A. Thomas, Techneg Clwyd Technics Ltd, The Coach House, Kelsterton Road, Flint, Clwyd CH6 5TH 0244. Tel: 810518/816236.

Communication and Environmental Aid for the Disabled (C.E.A.D.) C.E.A.D can be tailored to meet a wide range of functional needs. It can, for example, enable a severely physically disabled person without speech or sight to hold a conversation, type, use a telephone, raise an alarm, operate domestic electrical equipment etc. The system is simple to learn - the basic elements remain the same whatever the disability. However, users can define what functions they require, how the screen is displayed, and any special words they require in the speech dictionary. Presently the dictionary holds twelve hundred words. This will be expanded to two thousand in the near future. The system can be used by a number of people simply by changing the device used to input the information by the user, the cassette which holds the system parameters - such as how fast the system will operate, the format of the letters and words on the display, the speech dictionary etc. C.E.A.D. can be operated through whatever facility the person has. **SOFTWARE:** tape programme used with system. C.E.A.D. Supplies Ltd, 100 Southend Road, Gateshead, Tyne and Wear. Tel: 0632 823305. Software from D. Allen, Handicapped Persons Research Unit, 1 Coach Lane, Newcastle upon Tyne, NE7 7TW. Tel: 0632 664061.

Micromike. This is a modified C.B. microphone which may be plugged directly into the analogue input on the back of a B.B.C. micro. This gives simple voice volume control over a variety of games and activities aimed at the speech-impaired child. Software enables the Micromike to be used either as a simple voice switch or as a more complicated voice-volume indicator. The combination of volume, duration and timing can be used to encourage improvement in voice control. The programmes can also improve left/right co-ordination. **SOFTWARE:** (1) Introductory programme pack. (2) City. This enables the voice to draw a city skyline. The height, width and placement of buildings depends on volume, duration and timing of vocalisation. (3) Shoot. This operates in a similar way to 'City' using carefully timed vocalisation to play a shooting-gallery game. (4) Boat. The voice is used to steer a speedboat through the channel past some rocks. (5) Copter. Vocalisation apparently powers the rotors of the helicopter causing it to rise; pressing the Micromike switch causes forward motion. By the combination of these actions the user tries to rescue a man from his canoe by hovering the helicopter close over it. (6) Rider. Voice control is used to race a motorcycle past other motorcycles, whilst trying to remain on the track. (7) Speak. A programme to be used with Micromike. J. N. Tabberer, 51 Guernsey Close, Widnes, Cheshire WAs OYH. Tel: 051-423 1973. Software (1) - (6) from J. N. Tabberer: (7) from Dave Biggin, c/o Grimsbury Park School, Tower Road North, Warmley, Bristol BS15 2XL. Tel: 0272 673422.

Remote Control Overlay Keyboard. This is in prototype form. A 12" x 12" sensitive area is divided into 16 discrete areas, but can be arranged through software to operate in 1, 2, 4 or 8 areas. The board is sensitive to fingertip, pointer stick, or even a model car rolled over the surface. The main advantage is that there are no wires between it and the computer, thus allowing for greater flexibility of use. Where several overlays are in use the boards can be given an electronic identity which can be read by the computer, thus eliminating interference from similar adjacent equipment. **SOFTWARE:** programmes introduce concepts concerned with shape, colour, objects and

spatial representation. Nottinghamshire Schools Computer Development Centre, Birchover Road, Billborough, Nottingham NG8 4BN. Tel: 0602 283401. *Touch Sensitive Pad*. This is a highly sensitive 5" x 5" pad which can be used by most areas of the body to provide an input to a suite of programmes. SOFTWARE: ELSIE: "Early Learning Skills". Nottinghamshire Schools Computer Development Centre, Birchover Road, Billborough, Nottingham NG8 4BN. Tel: 0602 283401.

Other Software for Use with Single Switch Inputs

All of the following tape-cassette programmes have been developed by J.M. Leonard, 38 Court Drive, Shenstone, Lichfield, Staffs. WS14 OJG. Tel: 0543481163.

Autotype. This is a programme which enables a severely handicapped person to use a B.B.C. micro, together with a printer, to produce printed output of a professional quality. It operates through a single switch, which may be the space bar on the keyboard or an external switch.

Utility. This is a document storage programme used in conjunction with "Autotype".

Noughts and Crosses. A nought or cross symbol moves around the grid, at a pre-determined speed. When it reaches the desired square, a press of the switch stops it. The other symbol then moves round the vacant squares. A line is drawn through a completed row, and the score recorded.

Line of Four. This is a version of a game marketed under various names. Counters are placed alternately by the two players in one of seven vertical slots. The aim is to complete a line of four, either horizontally, vertically or diagonally. The method of choice is similar to that of "Noughts and Crosses".

Draughts. The traditional game with only minor variations to suit different conditions.

Fox and Geese. The geese start at the top of the board and try to trap the fox. The fox, who can move in any direction, starts on the lower half of the board and tries to break through the line of geese. The choice of moves is similar to the "Draughts" tape.